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ABSTRACT

Testimony of a hearing on health care reform, especially as it relates to women, children, and adolescents, is presented in this document. Statements and/or materials by these Representatives is included: Bill Barrett, Matthew Martinez, Mike Bilirakis, and Patricia Schroeder. Testimony and/or prepared statements and materials are included from these persons and groups: (1) Sarah Brown, senior study director, National Forum on the Future of Children and Families, Institute of Medicine, National Research Council, Washington, D.C.; (2) Edmund Haislmaier, policy analyst, Heritage Foundation, Washington, D.C.; (3) Robert Johnson, director, division of adolescent medicine, UMDNJ-New Jersey Medical School, Newark, New Jersey, and chair of the Board-The Center for Population Options, Washington, D.C.; (4) Richard Nelson, president, Association for Maternal and Child Health Programs, director, Child Health Specialty Clinics, and associate professor of pediatrics, University of Iowa, Iowa City, Iowa; (5) Kathleen Renshaw, parent accompanied by Marisa Harvey, Encinitas, California; (6) Joan, Mike, and Steven Weaver, Lorton, Virginia; (7) American Academy of Pediatrics, Washington, D.C.; (8) Margaret Feldman, Washington representative, National Forum on the Future of Children and Families, Institute of Medicine/National Research Council, Washington, D.C.; (9) Richard Flyer, chair, Emergency Medical Services for Children Coalition; (10) Steve Freedman, executive director, Institute for Child Health Policy, associate professor of pediatrics and health services administration, University of Florida, Gainsville, Florida; (11) Bob Griss, senior health policy researcher and co-chair, health task force, Consortium for Citizens with Disabilities, United Cerebral Palsy Associations; (12) March of Dimes Birth Defects Foundation; (13) Robert Sweeney, president, the National Association of Children's Hospitals and Related Institutions, Inc., Alexandria, Virginia; and (14) Elaine Walizer, Chagrin Falls, Ohio. (ABL)

HEALTH CARE REFORM: HOW DO WOMEN, CHILDREN, AND TEENS FARE?

ED348502

HEARING

BEFORE THE

SELECT COMMITTEE ON CHILDREN, YOUTH, AND FAMILIES HOUSE OF REPRESENTATIVES

ONE HUNDRED SECOND CONGRESS

SECOND SESSION

HEARING HELD IN WASHINGTON, DC, MAY 5, 1992

Printed for the use of the
Select Committee on Children, Youth, and Families

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HEALTH CARE REFORM: HOW DO WOMEN, CHILDREN, AND TEENS FARE?

TUESDAY, MAY 5, 1992

House of Representatives,
Select Committee on Children, Youth and Families,
Washington, DC.

The committee met, pursuant to call, at 9:30 a.m., in room 2226, Rayburn House Office Building, Hon. Patricia Schroeder (chairwoman of the committee) presiding.

Members present: Representatives Schroeder, Lehman, Martinez, Evans, Durbin, Sarpalius, Peterson, Cramer, Jr., Wolf, Holloway, Smith, Walsh, Klug, and Barrett.

Staff present: Karabelle Pizzigati, staff director; Jill Kagan, deputy staff director; Madlyn Morreale, research assistant; Carol Statuto, minority deputy staff director; Elizabeth Maier, professional staff; and Joan Godley, committee clerk.

Chairwoman **Schroeder**. Let's begin this morning. I want to thank you all for coming. We are very excited on the select committee because for the first time in 20 years we see serious discussions about health care going on in the United States and Congress. And there are dozens of bills. There is kind of a fast bill breeder reactor, kicking out more and more health care bills. And we also see lots of states trying very hard to figure out what to do.

What this committee wants to do is monitor what is being done and make sure that women, children and teens don't get lost in the shuffle. Very often those voices are not heard here. And we certainly don't want to end up finding out that the Congress has adopted something and then it is, oops, look at the oversight, we forgot to do this.

I think that any kind of health care that we adopt, whether it is employer-based, single-payer, or grounded in the tax system, must be sure that we are dealing with preventive care and we are dealing with families in a much fairer way.

We know the financial barriers that have been out there for many families. We know that 12 million children and adolescents and 9 million women of childbearing age have absolutely no health insurance. And then you add to those numbers a significant number of millions of people who have inadequate insurance.

So we see those in the private sector competing for more and more overworked staff and inaccessible clinics, and states that are squeezing their pennies very tightly. And so it becomes a very difficult problem.

We also have been looking in this committee at mental health problems and making sure that those be included, especially vis-a-vis adolescents.

Our last hearing was very discouraging because we found that we had for some adolescents absolutely no mental health care, actually for a large majority of them. And then for some of those who had any health care at all, there were a few who were being abused by the mental health care system.

So the question is how we make sure that all of those areas are included, also incorporating help for families to care for children who have disabilities or chronic illnesses at home. We also find it amazing that people get locked into jobs and can't move because of their insurance or that they have to choose between poverty or marital break-up to find some way to get the proper insurance for their families. All of those seem absolutely nuts to us.

I could go on and on and on with the different things that we have uncovered as we listen to people. But I think what we have today here are some very good experts who have been studying it, and we are looking forward to hearing from them. And we are going to lead off with some families who have been feeling it and we will have the people who felt some of the discrimination. And then we will have some of the experts talking about what to do.

So I think it will be an interesting hearing and this record will certainly help the select committee evaluate the different programs this body will be taking up.

OPENING STATEMENT OF HON. PATRICIA SCHROEDER, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF COLORADO, AND CHAIRWOMAN, SELECT COMMITTEE ON CHILDREN, YOUTH, AND FAMILIES

For the first time in 20 years, the nation has begun serious discussions about major health care reform. While action to date has been stymied over which approach to take, there are dozens of bills in Congress improving, modifying or discarding the current insurance system. Several States, despite serious financial constraints, are enacting their own statewide health insurance reform.

But as the debate progresses, my fear is that women, children, and especially teens will get lost in the shuffle. I am especially pleased that with this hearing, the Select Committee begins an exploration of the special problems of women, children and teens in gaining access to health care. The goal is to ensure that any health care policy that moves forward—whether it is employer-based, single-payer, or grounded in the tax system—knocks down the barriers that still keep so many from receiving the care, especially the preventive care, they need.

Financial barriers, including lack of health insurance, are by far the most common and significant reasons that women and children don't get adequate care. Twelve million children and adolescents, and nine million women of childbearing age, have no health insurance, and millions more have inadequate insurance.

There are other barriers keeping children and families out, even when they are trying their hardest to get the best possible care, including services that are unfriendly and often demeaning, inaccessible clinics with overworked staff, a critical shortage of private primary health care providers, a crumbling public health system, and bureaucratic hassles.

Under the current system, even families with health insurance don't get the basic preventive care they need, because many insurance policies won't cover immunizations or well-child doctor visits, or even maternity care. Substance abuse treatment or mental health services for teens are not only in short supply, but private insurance often won't cover those services either. And families struggling to care for childen with disabilities or chronic illness at home, are often forced to choose between poverty, institutionalization, or marital break-up because of limitations in their insurance policies.

Add to this maze the growing complexities and social ills that afflict millions of children and teens across the nation. High infant mortality and shockingly low

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childhood immunization rates warn that the system is in crisis. AIDS, violence, and drug addiction terrorize our youth and add further stress to the current health care system.

How do most of the current health care reform proposals in Congress address these concerns? Is a universal insurance system alone sufficient to ensure access to care for women and children? Do these proposals also sufficiently ameliorate or eliminate all of the obstacles that prohibit children, teens and families from getting the care they need?

These are among the questions the Select Committee will attempt to answer today. I welcome the experts who have already compiled the criteria we need to evaluate the major reform proposals under consideration by the Congress and the states and look forward to their testimony. I especially want to welcome the families who have confronted the system head on and been forced to retreat—and their families have suffered as a result. Their stories should motivate us to take immediate action.

No one should have to endure undue hardship just to obtain medical or support services for themselves or their children. Other nations have demonstrated that it doesn't have to be this way.

No pregnant woman in Europe has to ask how or where she will receive prenatal care or who will pay for it. Immunization rates among infants in countries like Botswana and Brazil far surpass what the U.S. has been able to accomplish. And, compared with our friends in Europe, we fall far short of offering families in need support services such as respite care or home visiting.

We already know that the U.S. is the only industrialized nation, other than South Africa, without a family leave policy that allows parents time off at the birth or adoption of a child, or to care for a seriously ill child.

I welcome all of you here today and look forward to your testimony. But most of all, I look forward to putting this information to good use in the pursuit of a health care reform policy that really works for children and families.

HEALTH CARE REFORM: HOW DO WOMEN, CHILDREN, AND TEENS FARE?

FACT SHEET

RISING HEALTH CARE COSTS THREATEN AMERICAN FAMILIES

- In 1991, the U.S. spent an average of $6,535 per family for health care expenses, of which families paid two-thirds (66%), and businesses paid the remainder. Between 1980 and 1991, average health payments by families increased by 147%. In 1991, average health care expenses consumed 11.7% of family income, up from 9% in 1980. By the year 2000, health care costs will consume a projected 16.4% of average family income. (Families USA Foundation, 1991)

- During the past decade, the proportion of employers who paid 100% of the annual premium for family coverage declined from 51% to 23%. Between 1980 and 1991, the share of employer-sponsored health insurance premiums paid by employees increased from 18% to 23%. (Congressional Research Service, 1992; Families USA Foundation, 1991)

MILLIONS OF CHILDREN, TEENS, AND WOMEN LEFT UNINSURED

- In 1990, an estimated 12.2 million children and youth under 21 had no health care coverage. Almost one-third of Hispanic children and nearly half of African-American children are not covered by private or public health insurance compared with 17% of white children. In 1988, one out of three poor adolescents (ages 10-18) was not covered by Medicaid. (Employee Benefit Research Institute [EBRI], 1992; National Black Child Development Institute, 1991; Delgado, 1991; Office of Technology Assessment [OTA], 1991)

- Two-thirds of children under 18 who lacked health insurance lived in families with incomes above the Federal poverty level. In 1990, two-thirds of uninsured children and teens under age 18 were in families whose head of household was employed year-round and one-fourth were in families where the head of household was insured. Children were most likely to be uninsured if their family head was either working in a business with fewer than 25 employees (27%) or self-employed (24%). (EBRI, 1992)

- One in four women in their childbearing years has no health insurance coverage for maternity care. In 1990, an estimated 433,000 women who delivered babies had no health insurance. (Institute of Medicine [IOM], 1988; National Commission on Children, 1991)

CURRENT HEALTH CARE/INSURANCE SYSTEM FAILS TO PROTECT CHILDREN AND TEENS

- In 1991, only 43% of children had been adequately immunized against childhood diseases by age two, according to a survey of children in nine cities. In 1989, only 45% of employment-based, conventional health insurance plans and 62% of preferred provider organizations provided coverage for basic childhood vaccinations. (Cutts, et al. 1992; National Vaccine Advisory Committee, 1991)

- Only one in five children who need mental health treatment and less than one in eight adolescents who need alcohol or other drug abuse treatment receive it. Private insurance plans are more likely to limit coverage for mental health and substance abuse treatment than other physical health problems; a recent survey of corporate benefit decision makers found that more than half predicted restricting or excluding dependent coverage for mental health and drug abuse treatment services. (U.S. Department of Health and Human Services, 1990; National Association of State Alcohol and Drug Abuse Directors, 1990; OTA, 1991)

CHILDREN AND YOUTH WITH DISABILITIES AND THEIR FAMILIES FACE SPECIAL HARDSHIP

- In 1988, nearly 20 million children under age 18 were reported to have one or more chronic illnesses. Of this population, an estimated one million children had severe chronic illnesses, and accounted for 19% of physician contacts and 33% of hospital days related to chronic illness. Two-thirds of disabled children have private health insurance, but only three of every five disabled children living in poverty are covered by Medicaid. Overall, nearly one half million disabled children are without any form of health insurance. (Newacheck and Taylor, 1992; Newacheck, 1990)

- Despite the fact that youth with disabilities make almost three times more physician visits annually, and spend 6 to 9 times as many days hospitalized as their nondisabled peers, one of every five disabled young adults (ages 19-24), and one of every seven disabled adolescents (ages 10-18), are uninsured. (Newacheck, 1989; McManus, Newacheck, and Greaney, 1990)

- Children with disabilities are often unable to qualify for private coverage due to pre-existing condition exclusions and waiting periods used by a growing number of employers. In a study of 713 children with chronic illness, 10% of parents had health insurance which excluded coverage for some or all of the child's care and 20% had medical debts. Half of the children failed to receive preventive or habilitative care. (Maternal and Child Health Policy Research Center, 1992; Birnbaum, Guyot, and Cohen, 1989)

- In a survey of parents of disabled children, 54% reported dissatisfaction with their medical insurance and 40% reported significant aspects of home care were not covered. Cost savings to Federal, state, and local government resulting from a transition to home care from a hospital or long-term care setting range from $100,000 to $170,000 per child annually. (Human Services Research Institute, 1989; McGauley, 1989)

MILLIONS OF CHILDREN AND FAMILIES LACK ACCESS TO BASIC HEALTH CARE

- In 1990, 43 million Americans lacked access to primary health services due to their economic situation, health status, or geographic proximity to primary care providers. More than three-fourths (78%) of the medically underserved reside in urban areas. However, rural counties were 2.8 times more likely than urban counties to be medically underserved. (National Association of Community Health Centers, 1992)

- Seven million children do not receive routine medical care. Children from low-income families are less likely than other children to receive physical examinations, vision testing, immunizations, and dental care. (National Association of Children's Hospitals and Related Institutions, 1989; Newacheck and Halfon, 1988)

- Adolescents ages 10-18 are less likely to utilize private office-based primary care physicians than any other age group, averaging 1.6 visits per person per year. White adolescents made 89.2% of all visits to private office-based physicians, compared with 8.7% by African-American youth and 7.3% by adolescents of Hispanic ethnicity. (OTA, 1991)

UNINSURED RECEIVE LESS HEALTH CARE AND ARE LESS HEALTHY

- Babies whose parents have no health insurance are 30% more likely to die or be seriously ill at birth, according to a study of more than 100,000 births in the San Francisco Bay area. Among nearly 30,000 sick newborns treated in California hospitals, those without health insurance were discharged from the hospital 2.5 days sooner than insured infants, and received services that cost 28% less. (Braveman, 1989; Braveman, et al., 1991)

- A 1989 survey of 1,066 Massachusetts households found that uninsured children and teens (under age 18) made 50% fewer physician visits per year and were more than 50% less likely to be hospitalized than children who were insured. One in ten residents who lacked health insurance reported not obtaining medical care due to financial reasons, compared with 1% of those with insurance. (Blendon, et al. 1992)

- In 1989, one-fourth of babies born had mothers who did not obtain prenatal care in the critical first trimester. Two-thirds of women without health insurance do not begin prenatal care in the first trimester, compared with one-fifth of privately insured women. (National Center for Health Statistics, 1991; American Academy of Pediatrics, 1989)

- The uninsured are 33% more likely to be in fair or poor health and nearly twice as likely as those with health insurance to lack a regular source of health care. Uninsured persons also have 27% fewer ambulatory visits and a slightly higher rate of medical emergencies. (Freeman and Blendon, 1987; Robert Wood Johnson Foundation, 1987)

HEALTH CARE PROVIDER SHORTAGE LIMITS HEALTH CARE ACCESS

- Over the past decade, the number of communities facing severe shortages of primary health care practitioners has remained unchanged. More than 33 million Americans live in areas designated by the Federal government as health professional shortage areas. (Robert Wood Johnson Foundation, 1992)

- Between 1978 and 1989, the percentage of pediatricians who accepted Medicaid patients decreased from 85% to 77%. Nearly 40% of pediatricians who accepted any Medicaid patients during

1989 reported limiting their access to care, an increase of 52% since 1978. (Yudkowsky, et al., 1990)

- The majority of adolescents receive their medical care from providers who have not received subspecialty training in adolescent health. There are estimated to be only one adolescent medicine specialist for every 20,500 adolescents and one adolescent psychiatrist for every 5,000 adolescents. (OTA, 1991)
- In 1988, nearly two-thirds (62%) of rural counties reported having no obstetrician and a slightly greater number reported having no pediatrician. (Center on Budget and Policy Priorities, 1991)

NUMEROUS OTHER BARRIERS TO HEALTH CARE IMPEDE ACCESS FOR CHILDREN AND FAMILIES

- When insurance status and financial factors are held constant and services are accessible, differences between poor and nonpoor families' utilization of health care almost disappear. (Klerman, 1991)
- Among women who received inadequate prenatal care, transportation difficulties were cited by 23% as a barrier to care, while 22% cited fear of doctors, 16% cited lack of child care, 10% reported cultural biases against male providers, and 7% cited inability to arrange time off work. (General Accounting Office, 1987)
- Nonfinancial and nonlegal barriers to health care for adolescents include lack of availability and willingness of physicians to treat adolescents, inconsistencies between adolescents' perceived needs and the care provided by physicians, adolescents' concerns about confidentiality, and physicians' and other health care providers' lack of competence to identify and treat the health problems of teens. (OTA, 1991)

May 5, 1992

Chairwoman **Schroeder**. I want to welcome the very esteemed member from Florida, who keeps thinking he is going to retire but we are not going to let him, who has been here and has worked very hard in the area of children, youth and families all along.

Congressman Lehman, do you have anything you would like to add this morning?

Mr. **Lehman**. Thank you, Madam Chair. This morning on TV there was a doctor on the Today Show and he talked about the best thing to do for health care is to eliminate smoking cigarettes. And unfortunately, there are many more women, especially low and middle income women, who are increasing the use of cigarettes. And I think we ought to do something about the danger.

The doctor on TV today said it is the leading cause of heart problems. And I think the fact that they are advertised now in media that deal directly with low and middle income women and they, they want to expand that market, which is the worst thing you can do for health care. And I think we really have a problem with children and women and teens, and I am here on behalf of the old men too.

Chairwoman **Schroeder**. Well, we want to include everybody. So that is great.

We have two families that were to testify this morning. I don't think the Weavers are here yet. Is that correct? But if they do, we will just call them up to the table when they come.

The other parent and child that have come are Kathleen Renshaw and her daughter, Marisa. So we are very, very happy to have them come.

So if you would like to come up to the table, we welcome you. We have a place for both of you, Marisa. There you go. We welcome you both. And we will put your full statement in the record.

You can summarize, do whatever you want. The floor is yours. And we appreciate very much your coming forward to explain what the health care system has done to you.

STATEMENT OF KATHLEEN RENSHAW, ACCOMPANIED BY MARISA HARVEY, ENCINITAS, CA

Mrs. **Renshaw**. Thank you, Chairwoman Schroeder and members of the committee, for holding this hearing to elevate the health insurance crisis as it affects children throughout the United States.

My name is Kathleen Renshaw. My husband and I live in Encinitas with our daughters, Marisa, eight, and Kirsten, four.

My children were planned and born into an insured, loving environment. In 1986, when we discovered that Marisa had a blocked kidney, we went through a range of emotions that only someone that has been through it could understand.

The one thing that gave us peace of mind was that we thought we were insured and that would enable her the best health care available. Little did we realize the true crisis that was about to begin.

I had prided myself on being an educated consumer and I did considerable groundwork to ensure that we were insured under a group plan rather than an individual plan.

After thorough investigation, we purchased what was presented to us to be a group insurance plan through my university, UCSD. The alumni association endorsed and backed a group plan carried by Fireman's Fund.

Over a period of seven years, however, the insurance carriers changed four times and we learned at the worst possible time that this was an artificial group, established for marketing purposes only.

Shortly after Marisa's surgery we were informed by Central Life, then the current insurer, that our group plan was being segregated into two groups and we would be given an option to apply to the new group at a significantly lower rate. Being suspicious, yet wanting to minimize our financial costs, we applied and were rejected because of our claims history.

Subsequently, our annual premiums doubled from $3,500 to $7,000 annually. At that point in time we dropped my husband from the insurance policy to reduce our costs. Within three months, though, the insurance company raised our premiums back up to $7,000.

At the end of the year we took an assessment. Our insurance premiums had been increased 130 percent that year. The following year we received another 90 percent increase, and it kept going on. We applied to other companies and were rejected each time.

In 1990, when our insurance policies reached $16,000 with a $500 deductible on myself and the two girls, we had to drop. I have since learned that this is a common tactic employed by insurers to divide and dump undesirable risks.

Insurers segregate the high risk policyholders into a group targeted for massive premium increases, placing this group into a death spiral.

When families such as ours are priced out of their policies and forced to let the policies lapse, the insurer conveniently goes to the state department of insurance for rubber-stamped authorization to cancel the entire group due to high lapse rate.

At this point in time I was taking graduate courses in college toward a marriage and family counselor.

As a result of our uninsured status, however, it became necessary for me to reassess my career goals and move toward the teaching profession, which historically has had good benefits which offset some of the lower pay.

I am presently a part time guidance counselor in a kindergarten through third grade school, contracted for part time work because the budget does not allow for full time. As a part timer, I receive no benefits and I am waiting presently for a full time teaching position to open.

We live in fear of an unforeseen illness or accident that could bring us to poverty. Presently, Marisa qualifies for catastrophic coverage for kidney-related illness only through California Children's Services.

However, the means testing to qualify limits family income to $40,000 annually. Because of this, my husband has had to turn down jobs in order to limit our income and make us eligible for this program. Marisa is not covered for any other illness or accident that might happen.

After an exhaustive search, I was successful in getting an individual policy for my four year old daughter, Kirsten. Unfortunately, they also, because of our history, fine-tooth combed her medical records.

At the time she was two years old, and had had two colds. So they permanently excluded her sinuses. She also had been to an eye doctor once because I thought her eyes were crossing when she was a baby. Her eyes are fine. But they permanently excluded her eyes.

Today Marisa's world is happily filled with kittens, school and budding friendships. She is bright, full of hope and hopes to be a writer when she grows up. True, children's dreams do change as they get older. But under the present conditions, she will be relegated to working, indentured to a job, any job that will offer her benefits.

My husband, Bill, and I face the necessity of separating in order to qualify for a single income for CCS for Marisa.

Both of us forego medical treatment in order to pay for the girls. I have put off having a baseline mammogram in fear that something might happen and I will have a pre-existing condition and will not qualify when I first start to get benefits.

The situation has impacted us financially but has also torn deeply at the integrity and security of our family.

Next year, when both of our incomes are taken into account, Marisa will no longer qualify for CCS and we will have to possibly dissolve our family unit in order to access health care.

When children with pre-existing conditions reach the age of 18 or 21 and they no longer qualify for dependent coverage or state assisted programs, they fall into a black hole and are abandoned under the present system. They become part of the underclass of uninsurables. They face an additional volley of discrimination by employers.

If all avenues of private insurance remain closed for them, they can apply to wait-listed, state funded programs such as the major medical risk program in California or one of its counterparts in at least 25 other states. The problems with these are long waiting lists, a year's exclusion for pre-existing conditions, and higher premiums for less coverage.

The only other alternative, should catastrophic illness fall, is to depend on their families and friends to hold fund raising events in their behalf.

The ballooning presence of state funded insurance programs and fund raising efforts by disability groups and families speaks to the massive cost shifting created by the insurance industry's increasing practice of insuring only the healthy.

We live in a less than perfect world. Yet insurance companies will only accept perfection. People should not be punished or made to wear a scarlet R for risk.

Historically, America has espoused the family unit as the fundamental thread that shapes our lives and strengthens our values. Politicians often use the phrase, the children are our future. But where is their future without the basic right to medical care? To my family and millions of others, this is merely empty promises.

As long as we continue to exist in a political climate where state and federal legislatures and state insurance regulators choose to ignore insurance practices which discriminate against innocent children, the integrity of the American family looms at risk.

Two years ago I felt I had nowhere to turn. My alumni association would not return my phone calls. My local representatives had sympathetic ears. Doctors had sympathetic ears. But no one was there to help.

Today, I feel this may be changing due to the grass roots reform efforts such as VOICE, Victims of Insurance Company Errors, with whom I am working in California, and people such as the Representatives on this committee.

I sincerely hope that my testimony today and that of others will serve as a catalyst for legislation creating universal affordable access to health care for all children. Our future rests in your hands.

[Prepared statement of Kathleen Renshaw follows:]

Prepared Statement of Kathleen Renshaw, Parent, Encinitas, CA

Thank you, Congresswoman Schroeder and members of the Committee for holding this hearing to elevate the health insurance crisis as it affects children throughout the United States.

My name is Kathleen Renshaw. My husband and I live in Encinitas, California with our two young daughters, Marisa, eight, and Kirsten, who is four. My children were planned and born into an insured, loving environment. In 1986, when my eldest daughter Marisa was three, she was operated on for a blocked kidney. One can hardly find the words to describe the range of emotions a parent goes through when something of that magnitude happens to their child. The only thing that allowed us some peace of mind was that we had good health coverage which enabled her the best care available. Little did we realize that the true crisis was yet to begin.

I had prided myself on being an educated and prudent consumer, and did considerable groundwork to ensure that we would be covered under a group plan, not an individual policy. After thorough investigation, we purchased what was presented to us to be a group insurance plan, through my alma mater, the University of California at San Diego (UCSD). The UCSD Alumni Association endorsed and backed a group plan carried by Fireman's Fund. Over a period of seven years, however, the insurance carriers changed four times and we learned at the worst possible time that this was an artificial "group", established for marketing purposes only.

Shortly after Marisa's kidney surgery, we were informed by Central Life, then the current group insurance carrier, that our group plan was being split into two groups and we would be given an option to apply to the new group -- one that offered significantly lower rates. Being suspicious, yet wanting to minimize our increasing insurance costs, we applied for coverage under the new plan, and were summarily rejected. Subsequently, our annual premiums doubled from $3,500 to $7,000 annually and we were forced to drop my husband Bill from the policy. Although this temporarily decreased our annual premium, within three months, the insurer brought the annual premium back up to nearly $7,000. At the end of the year we took an assessment. Our premiumms had been increased 130% in one year. The following year we received yet another extraordinary increase of 90%. By mid-1990, the premiums for myself and my two daughters had spiralled to $16,000. With our annual insurance premiums far outstripping our annual home mortage payments, we were forced to abandon the policy. Our only other choice would have been to sell our home.

I have since learned that this is a common tactic employed by insurers to "divide and dump" undesirable risks. Insurers segregate the high-risk policyholders into a group targeted for massive premium increases, placing this group into a "death spiral". When families such as ours are priced out of their policies and forced to let the policies lapse, the insurer conveniently goes to the State Department of

Insurance for rubber-stamped authorization to cancel the entire group due to the high lapse rate.

At this point in time, I was in graduate school working toward a career as a marriage and family counsellor. As a result of our uninsured status, however, it became necessary for me to reassess my career plans and move toward the teaching profession, primarily for the insurance benefits offered through the school systems.

We now live in fear that an unforeseen illness or accident could bring us to impoverishment. Presently, Marisa qualifies for catastrophic coverage for kidney-related illness only, through California Children Services (CCS). However, the means testing to qualify limits family income to under $40,000 annually. Because of this, my husband has had to turn down jobs, in order to limit our income and retain Marisa's eligibility under the CCS program. Marisa is uninsured and virtually uninsurable for any other health problems which may occur.

After an exhaustive search, I was successful in procuring coverage for Kirsten with an annual premium of $500 and a $1,000 deductible. Her application was scoured for exclusions. Because she had had two colds for which she was treated and one doctor's visit to an eye doctor, her policy has a rider excluding all coverage for sinus problems and anything related to her eyes.

Today, Marisa's world is happily filled with kittens, school activities and budding friendships. She is bright, full of hope and has set her sights on a career as a writer. True, children's dreams change as they grow, but Marisa must wake up now to the reality that under our present system, her career choices will be indentured to procuring a job, any job, which offers insurance benefits.

My husband Bill and I may face the necessity of filing for a legal separation in order that I might continue to qualify under a single income for CCS for Marisa. Our situation has not only impacted us financially, but has torn deeply at our integrity and psychological security as a family. We foresee the day when Marisa will no longer qualify for CCS and we will have to legally separate or dissolve our family unit in order to access health care for her.

When children with a serious blemish on their medical history reach the age of eighteen or twenty-one and no longer qualify for dependent coverage or state-assisted programs, they fall into a blackhole and are abandoned, under the present system of private insurance. They become part of an "underclass" of uninsurables, and are subjected to an additional volley of discrimination by prospective employers. If all avenues of private insurance remain closed to them, they can apply to wait-listed and state-funded programs such as the Major Risk Medical Insurance Program in

California, or one of its counterparts in at least twenty-five other states. Their only other alternative, should catastrophic illness or injury befall them, is to depend on their families and friends to hold fund-raising events in their behalf. The ballooning presence of state-funded insurance programs and fund raising efforts by families and disability organizations speaks to the massive cost-shifting created by the insurance industry's increasing practice of insuring only the healthy. We live in a less than perfect world, yet insurance companies will accept only perfection. Something needs to be changed!

Historically, America has espoused the family unit as the fundamental thread which shapes our lives and strengthens our values. Politicians often use the phrase "the children are our future", but where is their future without the basic right to medical care? To my family and millions of others, this is merely an empty platitude. As long as we continue to exist in a political climate where state/federal legislators and state insurance regulators choose to ignore insurance practices which discriminate against innocent children, the integrity of the American family looms at risk.

Two years ago, I felt I had nowhere to turn. This is now changing, due to the grassroots reform efforts of such organizations as VOICE (Victims of Insurance Company Errors), with whom I am working in California, and through efforts such as those of this Committee. I sincerely hope that my testimony today and that of others will serve as a catalyst for federal legislation creating universal access to health care for all children and families in the United States.

Chairwoman **Schroeder**. Thank you very, very much. Marisa, did you have anything you wanted to add? Well, we are very happy to have you here accompanying Mom.

Are these the Weavers? Did you make it? Why don't you come up and sit down at the table. We welcome you. This is not an easy place to find. And we will put your statement in the record. And if you would like to proceed and summarize or whatever, we would be happy to hear your testimony.

STATEMENT OF JOAN AND MIKE WEAVER, ACCOMPANIED BY STEVEN WEAVER, LORTON, VA

Mr. **Weaver**. Yes, ma'am. I was told that my statement would be here typed somewhere. I don't have it.

Chairwoman **Schroeder**. Oh, okay. There it is. Thank you.

Mr. **Weaver**. Our son, Steven, was diagnosed as having juvenile diabetes around November of 1985. And we were lucky enough at that time to have medical coverage for Steve through my wife's employment.

About two years later my wife's company's contract expired, causing us to lose our hospital coverage. This happened yearly, and we worried about the continuation of our son's coverage.

I was about to get coverage at my employment, which was Sears Roebuck, Incorporated at that time. Unfortunately, we were told that because Steven had a pre-existing condition he would have to wait one year before his coverage would begin. I was assured by company officials that after one year there would be no problem covering him.

After one year we were told that first Steve would need to be proven to be completely under control medically. By this time, Steven had begun puberty, making controlling his disease nearly impossible.

Sears refused to insure Steve, although the company HMO, Kaiser, agreed to cover him completely. We had no choice but to go without coverage for Steven.

Steve has been without coverage now for about five years, costing our family at least $20,000 in out-of-pocket expenses. And that is a very low estimate. This has all but completely ruled out any hope of our dream of ever buying our own home, among many other necessities of life for our other three children, least important ourselves.

Our monthly dollar output for Steven's medical condition is about $300 to $500, and I believe that is also very low. This will continue for years to come.

I have since changed companies with hopes of getting coverage for Steve. I have taken a large cut in salary while working many, many more hours, because Montgomery Ward has told me that they would cover Steve. We also have a 90 day waiting period. We are just keeping our fingers crossed that we won't be disappointed once again. And we really don't have any way of knowing. We just really are keeping our fingers crossed.

[Prepared statement of Joan and Mike Weaver follows:]

PREPARED STATEMENT OF JOAN AND MIKE WEAVER, LORTON, VA

Chairwoman Schroeder and Members of the Select Committee,

Our son, Steven, was diagnosed as having Juvenile Diabetes around November of 1985. We were lucky enough at that time to have medical coverage for Steven through my wife's employment.

About two years later, my wife's company's contract expired causing us to lose our hospital coverage. This happened yearly, and we worried about the continuation of our son's coverage.

I was about to get coverage at my employment, which is Sears & Roebuck, Inc.. Unfortunately, we were told that because Steven had a pre-existing condition, he would have to wait one year before his coverage would begin. I was assured by company officials that after one year, there would be no problem covering him.

After one year, we were told that first Steve would need to be proven to be completely under control medically. By this time, Steven had begun puberty, making controlling his disease nearly impossible.

Sears refused to insure Steve, although the company HMO (Kaiser) agreed to cover him completely.

We had no choice but to go without coverage for Steven.

Steven has been without coverage now for about five years, costing our family at least $20,000 in out-of-pocket expenses. This has all but completely ruled out any hope of our dream of buying our own home, among **many** other necessities of life for our four children, least important ourselves.

Our monthly dollar output for Steven's medical condition is around $300 to $500. This will continue for years to come.

I've since changed companies with hopes of getting coverage for Steve. I've taken a large cut in salary while working **many** more hours because Montgomery Ward has told me they would cover Steve. We also have a ninety day waiting period. We are keeping our fingers crossed that we will not be disappointed once again.

Signed,
Mike Weaver
May 2, 1992

Chairwoman **Schroeder**. Well, we thank you very much. Mrs. Weaver, did you want to add anything?

Mrs. **Weaver**. That basically says it all.

Chairwoman **Schroeder**. And Steve, you came, too. Good. Well, we are glad to have you all here.

Well, let me see if others have questions. Congressman Lehman, do you have any questions?

Mr. **Lehman**. Just a brief one. I have a friend, a highly skilled medical technician. The company she worked for went out of business. And she is now in remission from cancer and she cannot get another job because the employers do not want to hire anybody with what they consider a medical risk because of the adverse affect on their insurance rates.

Now they can't discriminate in employment because of race or sex, or handicap, but there is discrimination because of past health problems. Have any of you run into those problems about job discrimination?

Mr. **Weaver**. Not as yet, I haven't, no.

Mrs. **Renshaw**. I try not to talk about our background in hopes that we won't be discriminated against.

Mr. **Lehman**. I only know of this one case but it seems to be a subtle pattern. And I think we should look into the job discrimination because of past medical history, even if you are in remission.

Mr. **Weaver**. Yes. I just wanted to say that I was very happy at Sears and Roebuck. I was doing very well.

Mr. **Lehman**. But you moved to Montgomery Ward?

Mr. **Weaver**. Sir?

Mr. **Lehman**. You moved to Montgomery Ward?

Mr. **Weaver**. Yes, sir. Only because of the health.

Mr. **Lehman**. Because of health care.

Mr. **Weaver**. Because of health, and we don't even know if that is true or not. But I was enjoying my job. There was a big future involved in that job at Sears. But the only reason I changed was to get coverage for Steve.

Mr. **Lehman**. If you were a single individual with health care problems, you might have had trouble switching.

Mr. **Weaver**. Yes, sir. That is true.

Mr. **Lehman**. Thank you very much.

Chairwoman **Schroeder**. Thank you. Congressman Peterson.

Mr. **Peterson**. One of the questions that came to mind. The company changed its policy four times in a very short time. Was it a small company? And was that at all attached to your circumstance? Was it a method of avoidance, if you will, because of the involvement that you had?

Mrs. **Renshaw**. I am not really sure. We are just now discovering that this has happened to other people, through the University of California Berkeley Alumni Association. We are just now uncovering that it may have happened with all the university alumni associations. And they are all managed by Association Consultants in Chicago.

So I am not quite sure, you know, whether that is why they changed or whether it is completely done for financial reasons.

Mr. **Peterson**. It seems to me, Madam Chair, that the right or the transfer of insurance companies is becoming more widespread than the process. In other words, the instability of all companies may be a factor here that maybe we should consider. But I appreciate the opportunity to be with you.

Chairwoman **Schroeder**. Thank you. Congressman Klug.

Mr. **Klug**. Thanks for coming and for making the trip. We all know what Washington traffic can be like. So my sympathies. And to the Renshaws.

If you could give me a sense—and I know this is in some ways very difficult for you to pin down, but if you would prefer to see some kind of arrangement set up where private insurance companies still stayed in business and we created kind of pools to help folks who are either uninsured or have the problems like you do, or whether you would like to see the government run the entire system. Just what is your general feelings on that?

Mr. **Weaver**. I think realistically your first suggestion, in my opinion, would probably be the best, because I don't like all the involvement of government in my life anyway, really.

We were willing to pay whatever reasonably we could for the hospitalization for Steve, you know. And we still are, which I think is the idea in the pool. And I really don't want anyone—you know, we weren't asking for anything free. We just want the opportunity. We were told that we couldn't get him individual hospitalization, that we would have to get it for the whole family at about three to four times the cost of what I was getting it through my company. But you know, like I said, we are very willing to pay for it, you know.

Mr. **Klug**. That is fine. I understand perfectly. Mrs. Renshaw.

Mrs. **Renshaw**. At this point in time I am probably open to anything that would work for us and anything that would access us. I know that there are benefits to having private insurance.

The thing that I am afraid of, because of our experience, is that there is not enough regulation, there is not enough accountability, toward the insurance companies, making them open up their books and tell why they are increasing costs. There is not enough regulation to stop rejection and discrimination at this point.

I don't think complete change comes overnight. People like to go with what they know. But at this point there is so much profit for insurance companies that they are looking only at that rather than helping people out.

We are willing to pay. That is not, you know, the problem at all. But it has to be contained to something that is affordable, without pre-existing discrimination.

Mr. **Klug**. Thank you both.

Chairwoman **Schroeder**. Congressman Smith.

Mr. **Smith**. Thank you, Madam Chair. I too thank you all for appearing here today. And I know it is not easy to come before the public and tell a story that is sometimes embarrassing.

But I think it is interesting, to tell you the truth, that both of you all are in a situation that is not necessarily being addressed by this select committee today.

In the case of Mrs. Renshaw, you actually had insurance and your justified criticism was that the insurance rates kept going up. It wasn't that you couldn't get insurance. It was about the fact that the insurance rates skyrocketed and forced you to have to drop it. Isn't that the case?

Mrs. **Renshaw**. Yes. But now we can't get insurance.

Mr. **Smith**. Now you can't get it at all.

Mrs. **Renshaw**. Right.

Mr. **Smith**. But you had it at least at one point.

Mrs. **Renshaw**. Right.

Mr. **Smith**. And the rates, in effect, put you out of the market.

Mrs. **Renshaw**. Right.

Mr. **Smith**. And I think that the complaint there may well be with the insurance companies and with their way of doing business, more than with the fact that you couldn't get it to begin with.

And in the case of Mr. Weaver, here you have an example of a company policy, Sears Roebuck, that prevented you from getting the adequate insurance you needed, whereas now you have a different company, Montgomery Ward, and it looks like they do have a different policy that might enable you to get the insurance that you want to obtain.

So it is not a situation in either of your cases where you couldn't get it. It is a case of where you had it and lost it because of a company policy or insurance rates, it was some outside factor I think that put you in sort of an adverse kind of situation. And I think that ought to be clarified for the sake of the committee, because I think in many of these instances it is an individual company's policy, with the difference between a Sears Roebuck and a Montgomery Ward, perhaps.

Or in the case of Mrs. Renshaw it is an insurance decision to increase rates and have a very small pool of perhaps high risk people that has put you in the position you are in. And if that risk was spread among a larger number of people, your insurance rates wouldn't have gone up so much and you might well have been able to continue to have that insurance.

And so in both of your cases, you are not the typical kind of situation that we are talking about, about so many people—you know, 35 million people who don't have insurance. There are a lot of reasons why people don't have insurance and it is not always the fault of the government or the fault of the system. It may well be the fault—Mr. Weaver, you are agreeing—of the company itself and their policies, for example. It doesn't excuse the situation but I think it does put it in perspective.

As far as what the remedy is, which is what we are trying to get to, there are all kinds of alternatives. It is not just a universal health system. That is certainly one option. Whether or not that would result in even higher costs and perhaps less health care is an open debate among many Members of Congress.

We might need to provide certain economic incentives. We might need to provide certain deductions to individuals who are in your position, that you might be able to deduct much of those premiums from your income tax, for example. We might provide economic incentives for companies to give you all the kind of coverage that you need. So there are a number of options that I think Congress can consider.

One thing I wanted to check with you all about. Mr. Weaver, I think you have already answered the question. You sort of favor getting government out of the picture and perhaps going to the private sector and providing them with certain incentives to provide the kind of coverage that you want.

Mrs. Renshaw, you mentioned you didn't care where the solution came from as long as there was a solution.

Mrs. RENSHAW. Well, I do care. It is just that at this point walking outside of the system, being locked out of medical care and medical access, we are at the point where any help would be a step in the right direction.

Mr. SMITH. Right. In other words, you are willing to pay insurance but it just has to be reasonable and accessible is your point.

Mrs. RENSHAW. Yes. And she must not face employer discrimination in the future, because right now small businesses are rated on the health of their employees.

Mr. SMITH. Right. I missed the first part of your testimony. Have you ever worked? Or were you employed at one time?

Mrs. RENSHAW. I was self employed as a photographer years ago and then I went back to graduate school towards a degree in marriage and family counseling. That was what I wanted to do. I would have been self employed, which my husband is, and I saw the many pitfalls of being self employed. So I reassessed and changed my educational direction to go towards the teaching profession, which would lower my income. It is very rewarding, though, and the benefits historically have been there.

Mr. SMITH. Right.

Mrs. RENSHAW. So, job changing was all to do with our health situation.

Mr. SMITH. As I understand, Mrs. Renshaw, a lot of the problem is with self employed individuals who can't get the insurance coverage that they need. And maybe that is an area where, you know, if you provide certain deductions or certain economic incentives, then they will have a reason to go out and get insurance and be able to be covered.

Mrs. RENSHAW. Yes. The other thing I wanted to say is, every day I deal with children who come from broken families and other unfortunate situations, and I see many of them locked out because they have lost the primary provider. They are locked out of the insurance system. Also, if they hadn't had insurance before, and have the smallest pre-existing condition, the insurance companies redline them for anything to do with that condition—you know, just like my daughter Kirsten, sinuses for a cold, eyes for going to an eye doctor.

Mr. SMITH. Okay. Thank you. Thank you, Madam Chair.

Chairwoman SCHROEDER. Thank you. Congressman Barrett.

Mr. BARRETT. Thank you, Madam Chair. I am pleased that you called this hearing this morning so that we can focus on some of the vital issues of maternal and child and adolescent health care. And I too am grateful for you folks appearing before the committee and sharing not only your thoughts but your resources as well.

I guess I have no specific questions at this time, Madam Chair, other than to ask that my statement become a matter of the record. Thank you.

Chairwoman SCHROEDER. Without objection, of course.

[Prepared statement of Hon. Bill Barrett follows:]

PREPARED STATEMENT OF HON. BILL BARRETT, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF NEBRASKA

Thank you, Madam Chair. I'm pleased you called this hearing to focus on the vital issue of maternal, child, and adolescent health care. Everyone present here today realizes that the future of this country rests squarely on the health and general well-being of our children. The goal shared here is to empower America's families, to provide access to the best and most effective forms of health care for each family, each mother and each child.

The United States boasts the best health care facilities, doctors, nurses, and medical technology, in the world. And yet I am appalled by the barriers which American families face in accessing quality care. Medical costs have skyrocketed, with the Health Care Financing Administration estimating health care expenditures to reach 15% of GNP by the year 2000. Families in rural areas suffer from a shortage of doctors, nurses, and hospitals, as do those in inner cities, thus preventing mothers and children from getting the preventative, comprehensive care which studies show save both lives and medical expenses in the long run. On top of all this, I've been told that some health insurance premiums have increased by 30 percent in just one year. Small businesses can no longer afford to insure employees and their families, particularly those with seriously ill children.

In short, something has to be done to make America's medical resources available to its children and its families. Positive steps have been taken by some federal programs and organizations, as our distinguished panel will demonstrate. But much remains to be done.

Competition is the driving force behind our nation's second-to-none technology and medical know-how, and obstructing it would be fatal in a very literal sense. At the same time, in order to take full advantage of our strengths we've got to bring some sense to the relation between health care provider and patient, by streamlining and coordinating administration, and by bringing about real market reform. Ten of my colleagues and I introduced a bill, HR 4054, which begins to fix the provider-patient relationship by giving small businesses, which employ the vast majority of America's uninsured, the same tax deduction for buying health insurance for their employees which larger businesses now enjoy. HR 4054 would also reform small employer insurance market practices to guarantee eligibility and renewability, restrict premium increases, and restrict pre-existing conditions and exclusions. It would contain costs through federal malpractice and product liability reforms—thus addressing a system in which doctors fearful of lawsuits pass the cost of wildly expensive malpractice insurance onto their patients, through fee hikes and the ordering of unnecessary, redundant tests.

In addition to these reforms, which work to decrease medical cost and provide health insurance for millions of the uninsured, efforts must also be made to make health care administration more efficient and uniform. Communities must be provided with the information necessary to take charge of their health care system; to demand the care which most effectively fulfills their needs.

And finally, continued support must be given to those federal programs which promote preventative health measures; especially those geared to the special needs of mothers and children. Programs sponsoring childhood immunization and infant mortality reduction, for example, are an excellent investment, since they save both suffering and funds in the long term.

I find it shameful that in the midst of so much technological progress, those who are most deserving of care, our nations' mothers and children, are not being served. Surely a medical system which can determine a child's sex before it is born can also find a way to provide comprehensive, quality health care for America's families. I thank our panel for coming forward today, to remind us of the special and urgent needs of America's women and children. It is vital that in our discussion of health care reform we do not lose sight of what should always remain our goal: access to comprehensive, quality care for America's families, and a health future for our children.

Thank you Madam Chair, and I yield back the balance of my time.

Chairwoman SCHROEDER. Congressman Martinez.

Mr. MARTINEZ. Thank you, Madam Chair.

It is interesting, we seem to recognize that there is a problem out there but we don't seem to find the solution to it. You know, one of the things that is obvious, and it should be obvious to everyone—and you mentioned it, it is obvious to you—that insurance companies are in business to make a profit. And the only way they can make the profit is to keep the rates higher and coming in faster than the claims they pay out.

No insurance company that I know of is about to try to take a loss by insuring the high risk. Whether it is automobile insurance or health coverage, they just don't want to insure the high risk. They will cancel people if they have too many claims, whether it is health insurance or auto.

There is no way that we can do anything about that. But I think there is a way we can provide health care for all the children. You know, the Federal Government has a fantastic health care plan for every one of its employees, tantamount to the pilot program for a national health care plan. You know, we have a state, Hawaii, which provides health care to every man, woman and child whether they work or not.

I don't know, if one state can do it, a state like Hawaii, why can't we move nationally on this. But we are not moving it.

I can empathize with you because I remember that I once worked for a company that had health care and that company closed up. I went to work one morning and it was just closed. The Federal Government had closed it, in fact. And we found ourselves without health care with five children. And my youngest daughter got double pneumonia. And you know, the hospitals were more interested in whether I had a policy coverage so they could make sure they would get paid than accepting that child who was in an emergency situation.

If it hadn't been for a real good doctor, Dr. Kraus, who called that hospital, you admit that child now, we don't know what would have happened. But we worried about it.

So I know what it is like to be without health insurance. And I made up my mind, I didn't care what it was going to cost me, I was going to get it.

I didn't have the situation that either one of you have, where you have an illness that is a matter of record that is keeping you from getting that health care. And I think that is wrong and we ought to do something about that.

You know, what we ought to do is, if an insurance company is going to make a profit anyway, whoever they insure—because I remember when I started my business, my employees needed and wanted health care, and I remembered my own situation. I shopped around until I found a group that I could join that would offer me group insurance as a small business and we got it for them.

You know, what those people valued more than anything else, more than the wages they earned, more than the days off they got, was that health care. That was the most vital thing to them then. It is the most vital thing to them today.

And yet, as my colleague from Texas has said, there are millions of people out there without health insurance, whether it is for your reason or just the fact that they work for a small employer who says he can't afford it. I don't believe it. I think everybody can afford it. One way or the other, you can afford it.

But then if everybody is able to get insurance, then what are you going to do about the companies that stop insuring people because they are high risk? You know, they have not been kept from raising the rates for those individuals. They do it all the time. But having some insurance at whatever rate—you just said that you would be willing to pay any rate to get the insurance.

You say you don't want the government to step in and do it, you know. But when people won't be responsible, who else is there to step in? It has got to be the government. We don't like it. I am like you. I was a small businessman and I didn't want government on my back, because I was responsible. But how about the people that are not responsible? Somebody has got to get them to do the right thing. And generally it is through some kind of law.

You know, if we don't like laws, then we should police our own situations and make sure that the people don't take advantage of people. Then we won't need the laws. The laws are there only to protect the people against the few that would take advantage. That is all.

Insurance companies take advantage. They have a captive audience. You know, people need that insurance. And if you have got anything, you have got to get insurance. I have got so much insurance it is coming out my ears. And those annual premiums are pretty heavy. But I can't afford to be without it. But at least I am fortunate, I can afford it. There are a lot of people out there that can't.

The Federal Government has a national plan for all of its employees. I don't see why we can't extend that to everybody out there.

But we hold these hearings and we talk about these things, and then we get into—excuse the expression—partisan fights sometimes, posturing who is going to come out the biggest hero to look best to the people, and never mind we don't get it done because it has got to be this way. We have got to cross every T and dot every I before we can get a bill passed out. And then when we finally get one passed out, we go to the floor and we say, this is the best we can do. And you know what? It is not good enough.

And you people come and you testify, hoping that something will happen. I hope so, too. I think the Chairwoman is very sincere about wanting to do something about it or she wouldn't be holding these hearings.

I think there are some people in Congress—maybe the public will finally force the Congress to move and act in providing national health care for our people, because it is long overdue.

Thank you, Madam Chair.

Chairwoman SCHROEDER. Thank you very much. Congressman Holloway.

Mr. HOLLOWAY. Thank you, Madam Chair, for holding the hearing and for our witnesses for being here.

Mr. Weaver, I noticed when Congressman Smith finished you looked like you had a statement you wanted to make or something you wanted to say along with the testimony that he had made and the other witnesses. Did you have anything you wanted to say?

Mr. WEAVER. Yes. I just wanted to make clear that I wasn't saying that I wanted the government to stay out or stay off my back. What I am trying to say is I want to do it myself as much as I can, and when I need the help, maybe from the government, I sure will ask for it. You know, I am not saying anything against the government, the government's involvement. It is just like asking a parent for help. You don't want to do that until it is absolutely necessary.

You know, I am able to do it. I have the income. I can get the insurance. I just need the help maybe, I guess, of the government, which I am getting now here. But I don't want the government just to jump in and do it for us or for me, but maybe give us some ideas of what we can do. That is all.

Mr. **Holloway**. Thank you. I don't have as much a question but to say I do serve on the Energy and Commerce, Health and Environment Subcommittee, which will very likely be one of the committees that will be marking up some type of legislation.

I hope we never go to socialized medicine because I don't think it is the answer in our country. I think we do have to do something. I believe there does have to be help for people who have children with pre-existing conditions. I do believe there has to be some type of catastrophic care for people in this country to ensure that you can get a policy and that you can get it for an affordable rate.

I do personally feel that every person in this country should be a part of whatever system we come up with. The government doing it for us is not the answer. I think that is our problem in this country today, is the fact that we try to do too much for everyone and we made basically a welfare generation out of a lot of our country. And I have to say that and I firmly believe that. I am sure people in this Congress would disagree with me, and that is our right and a difference in philosophy here. But I believe we have to make our people—and help them where they need help. And I believe there are many people out there today who do need help with insurance, where they cannot afford it, they cannot get it.

But I think we have to be careful that we don't go—everybody says Canadian system, let's go toward it. I hear tremendous problems in our committee testimony coming out of the Canadian system.

So I hope whatever we do here, we will proceed but we will proceed in a way that we do take care of the needs that are there but not to make it a point—inflation started when we came up with Medicare and Medicaid in health care. It was running at pretty well the same level as normal inflation until we came up with our government programs. And then at that point it skyrocketed.

So I would just simply say we have to be careful. I know there are people out there hurting. I know there are people that need help. I hope we do it in a manner to help them but not to make them dependent on government for their needs.

I don't know if anyone has anything you want to say in return.

Mrs. **Renshaw**. Yes, if I may. There is just one thing I hope that the government does do. I hope that it looks at and will hold in check any form of discrimination that might come up.

We are a country that does not condone discrimination and we have blatant examples of discrimination when it comes to insurance practices. Charging people with a pre-existing condition much more money is a form of punishment, for someone whose life is already hard.

Mr. **Holloway**. If I can interrupt, I don't think that is discrimination. I think that we have to do something, as government, to see that we help that person. But I don't think that is wrong on an insurance company. I think you have to make money, as we said. Business is out there to do it.

I think that is the role we have to play. I think that is where we have to come in, to see that the person who cannot either get it or the rates skyrocket because of the pre-existing condition, I think that may be the role that government has to play.

To say that they are wrong in doing it, they won't stay in business, I think, if somehow they don't cover their costs of a pre-existing. But I do believe maybe you have hit the nail on the head on where we have to go with government. That is to help the people who cannot get it or cannot afford to get it or where the rates—I think we have to have some type catastrophic, some type level that says that every family of two is entitled to get an insurance policy for $250 a month or something, where we guarantee that you can get one you can afford.

But to just totally take over the system in this country, I think we may lead to greater problems in doing so and I think our actual research and all in health care will totally end once we do.

Thank you, Madam Chair.

Chairwoman SCHROEDER. Thank you. Congressman Sarpalius.

Mr. SARPALIUS. Thank you, Madam Chair. I commend you for holding these hearings and hope that we develop a health care bill in which this committee will become very aggressively involved. We need to provide adequate health care for the children in this country.

It is a sad day when in this country of America, the land of opportunity, nearly a fourth of our children are living in poverty and a high percentage of them are uninsured.

I hope that this body will really start looking at the priorities of where we spend our money.

I met with some doctors this weekend, Saturday, in my district, and I asked them, what can we do to cut health care costs? And they told me about a new OSHA regulation affecting doctors. When doctors examine someone with exposed fluids, they have to wear a mask, a gown, and rubber gloves. This is an additional $20 cost to each patient.

We need to look at regulations and additional requirements that we put on health care. There are many, many things that we can do to help cut costs in health care. But we have got to start changing our priorities and focusing on some of the real problems in this country.

I had always believed that the philosophy of the American people was that—for an example, if you had a boat sinking, who gets off first? It is supposed to be women and children. But that is not the way a lot of people think today. And I hope we start focusing on the problems of our young people and try to give them an opportunity, the many opportunities that I was able to enjoy as a kid.

I just want to say thanks again for this hearing and I hope this committee will continue to be actively involved in health care.

Chairwoman SCHROEDER. I think we will. I don't think our witnesses know what a great attendance this is. But you don't find this on many committees.

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Congressman **Cramer**.

Mr. **Cramer**. Madam Chair, I don't have any questions at this point. I too want to thank you for conducting this hearing on this very appropriate subject matter. Thank you.

Chairwoman **Schroeder**. Thank you. Congressman Durbin, do you have any questions?

Mr. **Durbin**. No. Thank you.

Chairwoman **Schroeder**. Congressman Wolf?

Mr. **Wolf**. I have no comments.

Chairwoman **Schroeder**. I had just a few things that I wanted to add.

Mrs. Renshaw, you come from California. And we heard it was a wonderful state and you had this risk pool and that this couldn't happen in California. So what you are saying is it can happen in California, too?

Mrs. **Renshaw**. Yes. The risk pool is very new. It is a couple of years old. Because of the small amount of money that was appropriated, it really wasn't advertised that well. I just myself found out about it about four months ago. And there is I think at present a two year waiting list. There is a year's exclusion.

Chairwoman **Schroeder**. A two-year waiting list?

Mrs. **Renshaw**. Yes. There is a year's exclusion for any pre-existing condition.

Chairwoman **Schroeder**. After you get in?

Mrs. **Renshaw**. Yes.

Chairwoman **Schroeder**. So that is three years?

Mrs. **Renshaw**. Yes. And then the policy is, I think, 125 percent over the cost of a regular policy and it has a smaller dollar amount.

Chairwoman **Schroeder**. Now the other thing that you mentioned is that if things didn't get better soon, you and your husband might have to separate in order to get coverage.

Mrs. **Renshaw**. On paper, yes. We love each other very deeply. We care very much for our family. We put our family first. But under the present system, to ensure in case—at this point Marisa is healthy and she is thriving. But you know, potentially something could happen. And to ensure that she will have coverage for that, yes.

Chairwoman **Schroeder**. Have you applied for the risk pool in the interim?

Mrs. **Renshaw**. Yes.

Chairwoman **Schroeder**. So you are now in your three-year waiting period, I guess.

Mrs. **Renshaw**. Give or take, you know, depending on how many people turn it down or whatever. But this is the estimated time. I don't know if that will be the actual time.

Chairwoman **Schroeder**. Mr. Weaver, you are a wonderful person, trying very hard, and you are now waiting with your new employer, hoping when the time passes that this time the coverage will apply. I assume that you are as concerned as Mrs. Renshaw is about Steve's employment possibilities when he gets out there.

Mr. **Weaver**. Yes, ma'am.

Chairwoman **Schroeder**. I think that you both make an excellent point, that you educate the children in all of this and very few employers are going to hire them if they check off their pre-existing condition. And that is a form of discrimination that we have not really dealt with legislatively in this country. While we deal with all these other things, I think those are very, very good points.

Well, we thank you very much. We wanted you to be here because we thought it was so important to point out that while there is a tremendous number of people who don't have insurance because of their economic status, there are a lot of people who are willing to get it if they could just find it.

And to hear your story about what you have done employmentwise and changed and changed careers and scrambled around, and your spouse not being able to make as much money as you would like because of the caps and the limits to get any coverage at all, those are amazing. And I think you make some very good points.

I have always been very angry because I felt if this government was at all serious, there were two things they could do immediately to cut the cost of insurance. Number one, mandate that all insurance have one form. I mean, you could cut down the overall overhead tremendously. And the second, allow people to pick between two pools, those who would agree to arbitrate malpractice and those who insisted on litigating.

Those are the kinds of things that I think—I have got a whole list, the Schroeder reforms, but no one ever listens to me. But those, you could do those kind of things and then it is up to the person, and you are not discriminating against pre-existing conditions. You are letting people pick what they want to do.

But the fact that we allow everybody to have a gazillion forms and add all this administrative cost and everything, it just drives me crazy. It says to me we are not very serious at all.

Mr. HOLLOWAY. Madam Chair, may I say a word before you finish?

Chairwoman SCHROEDER. Sure.

Mr. HOLLOWAY. And I agree maybe with some of your reforms there, that we could do a few things to cut costs.

But I do believe that what we just said may hit the nail on the head again on California's problems. We are trying to come up with solutions. If we don't appropriate the amount of money—and I don't know that there is anyone in this House that is going to vote to appropriate the amount of money that it is going to take if we are going to go to a total socialized medicine program in this country. We are going to end up with the waiting lists.

We are going to end up with problems that we never thought we would have. And we are going to have people that are going to be going and paying for the costs that can afford it, and we are going to have people that can't afford to do it that are going to be waiting.

So I just think that it is very important that we realize that our answers are not always sometimes I think as simple as we want to make them or we are not willing to spend the money it is going to take. And the amount of money on this is absolutely astronomical, if we really look at it and see.

So I hope that we will look at different problems, if we can.

Yes, Mrs. Renshaw.

Mrs. **Renshaw**. The one thing is by lumping all the risks together, I think you do have a problem. You know, you will have a monetary problem. But by spreading the risks around, if you take the whole pool of the state, I don't think there would be a problem.

And I think that the cost containment will pass down to the medical establishment, because I know when we had insurance that the price of what we were billed was completely different to when we have to pay it by ourselves.

They reduce the price for us when they find out we don't have insurance at this point. We paid $30 for a pair of paper slippers for her when she was in the hospital, and it goes on and on. We were double and triple billed. And the insurance companies, when I called up to tell them that we were double and triple billed, said, don't worry about it, your insurance covers this. They were not willing to go in and correct those mistakes.

Mr. **Holloway**. There are reforms, without any doubt, that need to be made. But I just hope we will realize that our problems won't be totally solved when we get there, if we get our people on waiting lists for surgeries and all that we are going to need. So it is, I hope people realize—really, to me, the most complex problem we face here in Washington I think is this problem.

Chairwoman **Schroeder**. Well, thank you for being such a good consumer. I go around, when I do my health care speech, and offer anybody in the room five dollars that can tell me what they pay per month for medical insurance. And I find I don't have to hand out a lot of five dollar bills. It is amazing. We are not very good consumers. People who get it, it is just deducted, they pay it and they don't even think about it again. And that is the problem. You have got a lot of people not thinking about it and other people think about it all the time because they can't get into the pool.

Congressman Evans, did you have anything you wanted to add?

Mr. **Evans**. No.

Chairwoman **Schroeder**. Well, let me thank this panel. I thank you very much for putting human faces on these problems. And I think this committee is very dedicated to making sure we don't make those kind of mistakes, whatever we do. So thank you, hang in there, persevere, and we really appreciate it.

And Marisa and Steve, we appreciate your being here, too. Thank you.

We will call up the next panel this morning.

We have four people who have been studying this problem and hopefully can give us some light and direction.

First we have Sarah Brown, who is the Senior Director for the National Forum on the Future of Children and Families at the Institute of Medicine and National Research Council; we have Richard Nelson, and Dr. Nelson is the President, Association of Maternal and Child Health Programs, Professor of Pediatrics at the University of Iowa in Iowa City, Iowa; we have Edmund Haislmaier—I hope I didn't mess that up too badly—health care policy analyst for the Heritage Foundation in Washington, D.C.; and Dr. Robert Johnson, who is the Director of the Division of Adolescent Medicine in New Jersey Medical School, Newark, New Jersey, and he is also the Chair of the Board of the Center for Population Options in Washington, D.C.

We welcome this esteemed panel. We will put all of your statements in the record. And Ms. Brown, let's start with you and we will let you summarize or do whatever you would like. Welcome and thank you for being here.

STATEMENT OF SARAH S. BROWN, M.P.H., SENIOR STUDY DIRECTOR, NATIONAL FORUM ON THE FUTURE OF CHILDREN AND FAMILIES, INSTITUTE OF MEDICINE, NATIONAL RESEARCH COUNCIL, WASHINGTON, DC.

Ms. **Brown**. Good morning, Madam Chair and members of the committee. We are so gratified, all of us, to see an extraordinary turnout like this for a hearing on today's issue. As a long time warrior in maternal and child health, I want to tell you how gratified I and my colleagues are that so many of you take this issue so seriously.

I am a senior study director at the Institute of Medicine. And in concert with Dr. Richard Nelson (who, as you see, is also testifying this morning) and several other experts in maternal and child health, we recently released a report called Including Children and Pregnant Women in Health Care Reform.

In the written statement I have submitted, I have quite a bit of material about it, and I have also asked for the actual report to be introduced into the record. It is actually not very long.

Chairwoman **Schroeder**. Without objection.

Ms. **Brown**. Thank you very much.

In the few minutes I have this morning, I want to make a very simple point. Those of us who understand the day-to-day problems that children and teenagers and pregnant women face in getting health care have a very important responsibility and a very tough job at present. It is to educate our colleagues in the Congress and in other policy-making bodies nationally and in the states, too, about what a health care reform bill should include on behalf of this population.

We must speak clearly about maternal and child health issues, about the policy pitfalls and the day-to-day difficulties that this population faces in getting health care. We need to describe over and over again what we have learned about kids and health care through the work of this committee, through the Institute of Medicine, the work of the National Commission to Prevent Infant Mortality, and many other groups around town that have been active in maternal and child health over the years.

If we don't do that, I think it is possible—it may even be likely—that a health care reform bill will be passed that misses major opportunities to address a whole range of important maternal and child health matters. Madam Chairman, you made that point in your opening statement. I think you are absolutely right.

It is in this context that I think your hearing this morning is enormously important. It allows us all to celebrate the fact that serious change in health care may be in the wings, to point out simultaneously that the reform movement must pause long enough to listen to the special issues and problems posed by children, teenagers and pregnant women, and to address these topics as part of a broader solution.

Now what are these special topics? I am going to mention just a very few.

One. The benefit package included in the health care reform bill must be rich in preventive services: immunizations, family planning, well child care, full pregnancy care. These services can no longer be left out of benefit packages in the hope that individuals and families will somehow finance them on their own. Those days are past.

For example I recently paid $130 for an immunization for just one of my three children.

Two. The reform bill must include ways to place people and services in underserved areas. We know that simply putting an insurance card into the hands of more people will not solve the problem of absent providers and services. We are going to need a more aggressive approach.

The Community Health Centers Program, the National Health Service Corps, and numerous of related initiatives have taught us how to beef up care in certain communities. This experience needs to be studied and drawn on systematically in crafting a comprehensive reform of the health care system. Part of the strategy to increase provider availability should be the training of nonphysician providers: certified nurse midwives, nurse practitioners and others, whose services are less expensive than physician services, and who are very well suited to a wide range of practice settings.

The point is that expanding access to insurance is a first step, but not a sufficient step if access to health care (not just access to health insurance) is to be achieved.

Third. The reform bill must address some of the most odious practices of the insurance industry, such as the pre-existing condition exclusions we just heard about, experience rather than community rating albeit in a revised form, and waiting periods for coverage to begin.

This last issue, incidentally, bears directly on maternal and child health. Twenty million American women belong to insurance plans that require waiting periods of three months or more for coverage to begin. At the same time, we tell pregnant women to begin prenatal care early in pregnancy. So, what is it going to be? Is it going to be waiting periods for coverage to begin? Or is it going to be early prenatal care? The two are inconsistent.

Fourth. Particularly in the case of the more far-reaching reform bills, the whole place of the public health care system and all the many maternal and child health categorical grant programs must be addressed. It is complicated and it is messy. But it is unavoidable. These important programs include, for example, the maternal and child health services block grant, immunization grants, Title X monies, injury prevention, and many others. Are these programs going to be left as they are when the health care reforms are put into place? Are they going to be folded into a new health care system, a new financing system? Are they going to be eliminated because we now have insurance, at least in theory, available to everybody? And if we are going to eliminate them as part of a major overhaul, what is to become of the other functions that the public health programs perform: planning, data collection and analysis, and needs assessment?

Fifth. What is the bill going to say about undocumented residents in the United States, the majority of whom are women and many of whom are of childbearing age?

In states such as Florida, New York, California, Texas and Colorado, this uninsured population contributes heavily to the burden of uncompensated care, and, more generally, to many of the poor health status indicators in U.S. maternal and child health.

Sixth and finally. What protections will the bill offer against the current infatuation with managed care as the cost containment tool of choice?

Here in the District of Columbia and elsewhere around the country, for example, some managed care plans are limiting hospitalization following childbirth to 24 hours, even if the mother is 16, even if she has no real home to go to with her infant, even if she doesn't know the first thing about bathing or caring for her baby.

What is this bill going to offer in the way of quality assurance and common sense to protect against such cost control measures?

The list could be expanded, of course, of important topics that a reform bill should address: regionalized systems of perinatal care, graduate medical education, all the issues of privacy and informed consent that teenagers face when they seek health care, and so on. But the simple point remains, we have to make certain that whatever the reform bill passed, the needs of children, teens and pregnant women are carefully attended and at the same level of detail and the same level of force that we address ourselves to the hospital and the insurance industries.

I would be pleased later to answer any questions about this testimony. And Ms. Schroeder, I want to thank you again for allowing us to present the report before the Women's Caucus, which you cochair. That was very gracious of you.

[Prepared statement of Sarah S. Brown follows:]

PREPARED STATEMENT OF SARAH S. BROWN, M.P.H., SENIOR STUDY DIRECTOR, NATIONAL FORUM ON THE FUTURE OF CHILDREN AND FAMILIES. INSTITUTE OF MEDICINE/NATIONAL RESEARCH COUNCIL, WASHINGTON, DC

Good morning, Madam Chairman and members of the Committee. My name is Sarah Brown, and I am a senior study director at the National Forum on the Future of Children and Families, a joint project of the Institute of Medicine and the National Research Council. The Research Council is the operating arm of the National Academy of Sciences, the National Academy of Engineering, and the Institute of Medicine, and was chartered by Congress in 1863 to advise the government on matters of science and technology. I am here today to talk with this committee about several important ideas that emerged from a series of workshops recently hosted by the Forum to discuss health care reform from the perspective of children, pregnant women and teenagers.

As you well know, over the last several years, many important national organizations and public policy leaders have introduced blueprints for reforming the health care system. It has even become an issue of some prominence in the presidential primaries. But the complexity and constantly changing dimensions of national discussions about health care reform hold the risk that numerous important issues in maternal and child health will be overlooked.

Accordingly, the National Forum on the Future of Children and Families hosted a series of workshops to detail the needs of children, teenagers and pregnant women that any major reform of the nation's health care system should address. The workshops also explored seven reform proposals that are representative of the major ideas for reform currently being considered by the U.S. Congress and by others interested in health system reform. Five of the seven were "multipayer" plans, that is, they retain a mix of private health insurance and one or more publicly financed programs:

- The American Academy of Pediatrics (AAP) proposal, "Children First" (a version of the AAP proposal was recently introduced into the Congress by Congressman Matsui (D--Calif.) as "The Children and Pregnant Women's Health Insurance Act of 1991," H.R.3393);
- the American Medical Association (AMA) proposal, entitled "Health Access America;"
- the Health Insurance Association of America (HIAA) proposal, entitled "Health Care Financing for All Americans;"
- H.R. 2535, the Waxman bill, entitled "The Pepper Commission Health Care Access and Reform Act of 1991," introduced by Congressman Waxman (D--Calif.); and
- S. 1227, the Senate Leadership bill, entitled "Health America: Affordable Health Care for All Americans," introduced by Senators Mitchell (D--Me.), Kennedy (D--Mass.), Riegel (D--Mich.), and Rockefeller (D--W. Va.).

Two of the seven plans reviewed were "single-payer" plans, that is, they replace the current mix of public and private health care financing with a single public financing plan, with private insurers either replaced or retained as intermediaries only:

- H.R. 1300, the Russo bill, entitled "The Universal Health Care Act of 1991," introduced by Congressman Russo (D--Ill.); and

- H.R. 2375, the Stark bill, entitled "The Health Insurance for Children and Mothers Act of 1991," introduced by Congressman Stark (D--Calif.).

The participants believed that their assigned focus on children and pregnant women was well justified by data documenting their substantial representation among the uninsured. In 1989, 29 percent of the U.S. population was under age 21, but they represented 36 percent of the uninsured--12.4 million children under the age of 21 were uninsured in that year. In addition, the National Commission on Children has estimated that in 1990, 433,000 pregnant women had no health insurance, representing 9 percent of all pregnant women. Part of the explanation for such numbers is that many children and pregnant women are themselves not insured directly but are instead the indirect beneficiaries of a parent's or spouse's employment-based private insurance. Being one step removed from the source of insurance--that is, receiving coverage as a dependent--is an increasingly expensive and insecure basis upon which to receive health care coverage. Because of the increasing cost of dependent insurance, employers are ever more reluctant to meet the full cost of that coverage, asking instead that their employees pay a larger proportion of additional coverage. In 1980, for example, 40 percent of employers paid the full cost of dependent coverage; in 1990, only 33 percent did so. Such trends underlie the finding that 23 percent of uninsured children live in families with insured parents.

These data also supported a consensus among the participants that, over time, the health care needs of children and pregnant women will best be served by a policy that avoids pitting the relatively modest needs of this population against other populations and health care demands.

The participants discussed, for example, the current practice in the Medicaid program of placing flat dollar and duration limits on coverage of ambulatory services but not on coverage of long-term care services--a practice that has led many state Medicaid programs to spend an ever larger share of their funds on the elderly, further reducing resources for children and pregnant women, who rely primarily on ambulatory services.

A summary of the workshops, "Including Children and Pregnant Women in Health Care Reform," presents some eleven health policy issues that the workshop participants defined as being important to pregnant women, children and teenagers, and comments on the ways in which the seven proposals address the 11 goals. With your permission, I'd like to enter the full summary of those workshops in to the record. I'd also like to take this opportunity to again thank you, Mrs. Schroeder, for allowing the Forum to brief the Congressional Women's Caucus about this paper the day it was released to the public.

Rather than simply recite the goals to you, I'd like to underscore six of the eleven, and give you some concrete examples of troubling issues that are at the heart of each, lest they sound too abstract and general.

Goal 1. **All children and pregnant women have continuous access to health insurance.**

However straightforward this goal, it remains elusive under present arrangements. Coverage by private health insurance often requires individuals and families to meet such requirements as a minimum length of time employed (for example, 20 million women belonging to health insurance plans that require waiting periods of three months or more for coverage to begin, which can preclude coverage within the first critical trimester of pregnancy), good health status, a particular degree of relationship to a covered person, lawful U.S. residence, and so forth. The Medicaid program also imposes a wide variety of preconditions centering on income, residence, age, family composition, and other factors. Failure to satisfy one or more requirements can cause pregnant women and children to be ineligible for coverage altogether or ineligible for coverage for a period of time or for certain conditions.

Principally for reasons of cost containment, health insurance plans may exclude certain groups with special relevance to maternal and child health; in some instances, legal concerns form the basis for exclusions (as when health insurance is not available to children in certain types of custodial arrangements). These groups include adolescents and young adults not yet insured on their own who have attained the age of majority as defined by their parent's insurer (and who do not receive coverage through one of the exceptions provided in the insurer's plan, such as enrollment in college); undocumented U.S. residents; adopted children; children who are not related closely enough to their caretakers to be covered by the caretaker's insurance plan (for example, children living with a grandparent or older sibling); and dependent adult children (such as a chronically ill adult living with his or her parents).

The exclusion of undocumented residents is of special relevance to maternal and child health because many of these persons are mothers, children, and pregnant women. Of the 2 to

4 million undocumented people in the United States at present, the majority are women. Women of reproductive age (15 to 44) are believed to comprise 30 to 40 percent of the total; 20 percent are believed to be children under 15.[7] More generally, the need to provide undocumented residents with a source of payment for health care is suggested by their significant contribution to the uncompensated care debt reported by hospitals in such states as Texas, California, Florida, New York, and Illinois, where there are large populations of such individuals.

This important concept of continuity also requires that individuals be able to move easily among and between insurance plan, if a multi-payer system is retained. It will be important that a reform plan describe in some detail how continuity and portability is to be ensured when multiple systems co-exist.

Goal 2. Coverage is provided for a continuum of services that emphasizes primary and preventive care and includes the diagnosis and management of a variety of diseases and conditions, as well as specialized care to handle complex health problems.

Few issues have proved as contentious in health policy as benefits packages. What seems an essential benefit to some is marginal to others, especially when cost is at issue. There are at least two overlapping issues related to covered benefits: (1) defining the services that should be covered by health insurance and then ensuring access to important, medically necessary services that fall outside a benefits package; and (2) addressing the problem of noncomparable benefits across insurance plans, especially public versus private ones.

The first subtheme--what is to be in the benefits package--is enormously important to maternal and child health. For example, few, if any, private plans cover many of the benefits that children with chronic illnesses and handicapping conditions receive through state Medicaid plans, and immunizations offered as a part of well-child care are commonly not covered. Not surprisingly, there have been major measles outbreaks in recent years; more than 26,000 cases of measles were reported in 1990 (100 of which resulted in death), mainly among poor, inner-city children, a major increase over the average of 3,000 cases a year between 1981 and 1988. Similarly, family planning services are commonly excluded despite the high rates of unintended pregnancy in the United States, and the clear cost-efficiency of pregnancy prevention.

The point here is that preventive services--and primary care services, too--must be included in the benefits package. The notion that costs for such care is minimal and that families should be expected to budget for such expenses is no longer reasonable, given the high costs at present of, for example, immunizations and prenatal care.

The second subtheme is also very important, though a bit dull. Reform proposals that retain a publicly financed program alongside a private system--the multipayer plans--present the additional problem of noncomparability of covered services between the public and private plans. There are, of course, differences in benefits among the hundreds of private plans now in existence, but the differences between public and private packages are generally more extreme. The importance of this issue is thrown into sharp relief when comparing the broad range of services that many Medicaid programs now support with the benefits packages typically offered through commercial insurers. For example, recognizing the special needs of low-income people, Medicaid often helps to pay for transportation to a health care facility, many home health care services, comprehensive dental care and eyeglasses for children, and extensive mental health services--services commonly excluded or highly limited in private plans. Similarly, Medicaid's Early and Periodic Screening, Diagnosis and Treatment program (EPSDT) has been used to finance such services as orthodontia for children with significant dentofacial problems and therapeutic day nurseries for developmentally disabled infants and toddlers.

Accordingly, in the case of multipayer plans, it may be desirable to require that benefits provided by public and private plans be essentially identical if the package is comprehensive. If not, it may be preferable to provide a more generous package under the public plan in order to accommodate the greater needs of the low-income individuals more likely to enroll in it. In particular, it is important to ensure that poor children and pregnant women are not worse off with regard to covered benefits under a new plan than under Medicaid. In the case of single-payer plans, which typically eliminate Medicaid and present a limited basic benefits package, the question of how existing Medicaid benefits are to be handled is pressing.

Goal 3. Health services are provided by qualified providers in a wide variety of settings that are effective in caring for children and pregnant women, especially the medically underserved. Similarly, the number and diversity of qualified providers offering services to this population are increased, particularly for those who are poor, high-risk, or living in inner-city or isolated rural areas.

One of the clearest points of consensus among our group was that simply expanding access to insurance was not enough to meet the needs of the groups we're discussing this morning. Although having a payment source available is a critical first step, it is only that. If there are not enough people and services available to these newly insured individuals, we have accomplished little. Accordingly the summary gives special attention to the challenge of "resource development." Several settings that are well suited to providing care to children and pregnant women are not routinely supported by private third-party payers, and grants to establish and maintain them are often inadequate and unreliable. For example, school-based health clinics serving adolescents, birthing centers, comprehensive community-based health centers, and home-based care for certain diseases and conditions have proven both economical and effective, yet have limited support.

The importance of supporting multiservice centers for medically underserved populations deserves special comment. Extensive experience over the last two decades has demonstrated that meeting the health needs of high-risk pregnant women and children, particularly the very poor, is often accomplished through a mix of intensive medical and social services provided at a single site. Comprehensive community health centers (CHCs), migrant health centers (MHCs), maternal and child health services in local health departments, school-based clinics, and similar organizations can blend the various services needed by high-risk individuals into units understandable to both consumers and providers. Typically, these centers offer comprehensive medical, health, and social services; rely on the skills of a variety of health professionals; have adequate staff for assessment of community needs and for recruitment, tracking, and follow-up of patients; provide health education, transportation, and translation services; serve a clearly

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defined geographical area; offer care that spans the developmental sequence from pregnancy (including family planning and preconception care) through childhood, using the family as the basic unit of service; and provide the option of home visiting for high-risk individuals, particularly pregnant women and families with young children. Despite the proven value of such comprehensive centers for high-risk families, they have never had a secure base of funding, and their numbers have always been limited. For example, about 550 CHCs and MHCs are currently in operation; only 6 million of the 32 million Americans who are medically underserved receive care through these systems.

Similarly, there are not enough well-trained, licensed providers to care for children and pregnant women who are low-income, medically high-risk, or living in inner cities or rural areas. For example, over the last several years, the number of obstetricians serving these groups and these areas has declined, as has the number of family physicians practicing obstetrics; the latter provide over two-thirds of the obstetrical care in rural areas. A slight decline in the number of pediatricians who take Medicaid patients has also been noted recently. Workshop participants did not discuss in detail whether these trends reflect provider distribution patterns that do not match need or, rather, an absolute deficit in numbers of providers. However, the consensus was strong that, with the exception of certain mid-level providers, overall supply of health care providers is adequate, but that they are not always found in sufficient numbers in areas of greatest need.

This problem of "provider maldistribution" is exceedingly complicated, reflecting long-standing patterns of practice and payment. Although a single reform plan may not be able to solve this problem quickly and efficiently, it should nonetheless offer some constructive steps. One time-tested method of addressing the provider distribution problem is to fund special clinics in underserved areas, as just noted. Five other solutions are: (1) the direct placement of health care providers in medically underserved areas through the National Health Service Corps and similar programs; (2) the use of midlevel practitioners in appropriate settings; (3) solutions to the medical liability situation; (4) encouraging private providers to accept more patients whose care is paid for by public funds; and (5) increased emphasis in graduate medical education for health professionals on primary and community-based care rather than on tertiary care.

Goal 4. The future role of existing government grant programs in maternal and child health is explicitly considered in reforming the health care system, with regard to both the personal health services supported by these grant programs and to their planning, evaluation, and training functions.

Expanding the availability and affordability of health insurance intensifies the ongoing debate about the future role and structure of the public health system in providing personal health services, and it raises specific questions about the fate of many grant programs funded through the Public Health Service (PHS), the Social Security Administration, and other authorities. Examples of such programs that are especially important to children and pregnant women include:

- Title V, the Maternal and Child Health Services Block Grant,
- the Preventive Health Services Block Grant,

- Childhood immunization grants to states,
- Health services that are part of special education programs,
- Pediatric emergency medical services,
- Title X family planning services,
- Pediatric AIDS health care demonstration program,
- Injury control grants,
- Grants for lead poisoning prevention and abatement, and
- Poison control activities.

Many of these programs provide health services to those with no source of payment for health care, serving in some instances as providers of last resort. Some of these programs serve special populations or provide important health services that third-party reimbursement does not cover. Many of them address such community-level problems as prevention of lead poisoning and traumatic injury, not easily handled through one-on-one health services financed by traditional insurance. These grant programs can be innovators in systems that provide few incentives for coordinated, interdisciplinary care (for example, special services for children with multiple handicaps), and have the capacity to move easily across traditional boundaries between health and other human service and educational areas. In addition, they often carry out community-level planning, needs assessment, data collection and analysis, and training--tasks that cannot easily be assumed by individual providers of care.

Given the importance of these public health grant programs, their future role should be considered in reform proposals. Are they to be eliminated? Folded into the new public system? Retained as is? If the intent is to fund all, or most, personal health services through insurance, what is to be the fate of the functions that public health grant programs often encompass? Are some services best financed and regulated through public health systems but provided by private institutions and individuals? Answers to these questions pertain directly to the future course of the public health system, of which maternal and child health services are only a part. In practical terms, bringing some order to all these programs and defining their relationship to a new financing system will be exceedingly difficult, not only because each has its own bureaucracy and constituency, but also because not all are under the jurisdiction of the same congressional committees.

Goal 5. Cost management measures accommodate the special needs of children and pregnant women.

One of the most popular approaches to cost containment in current proposals for health care reform is managed care. It deserves special comment because of its growing popularity as a tool for containing costs for privately insured as well as Medicaid-insured children and pregnant women.

From the maternal and child health perspective, the critical issue is whether managed care arrangements meet the health care needs of this population. Limited data and anecdotal experience with managed care for children and pregnant women identify several concerns. First, there remain some questions about the proper role of the "gatekeeper" function for a pediatric population. In some instances it may be helpful, as for children with chronic illnesses whose access to primary care services may be facilitated by health maintenance organizations (HMOs), for example; in others instances, the result may be less favorable, as when managed care networks conflict with existing systems for triaging and transporting seriously ill newborns. Second, managed care networks may place strict limits on access to providers who are not enrolled in the plan, even when their skills are not available from plan providers; although such limits may be appropriate for essentially well children, they can pose major obstacles to needed care for children with more serious and rare diseases and conditions. And third, managed care can generate conflicts between the fundamentals of good medical care and the pressures of cost containment (as exemplified by the growing practice among managed care plans of denying more than 24 hours of hospitalization after a normal vaginal delivery and limiting coverage of postpartum home-based nursing care for early discharge patients).

Goal 6. The administrative complexity of the health care system is substantially reduced from the perspective of both providers and consumers.

Frustration with the complexity of the current U.S. health care system is one of the strongest forces pushing the reform debate. The administrative tangle of multiple programs and sources of funding creates its own barrier to care and contributes to costly inefficiency. This is a problem for all populations, but particularly for children and pregnant women. Children must depend on adults to arrange for their health care; but if these adults cannot or will not arrange for needed services, children have few tools available to them to secure the care they need or to advocate on their own behalf. And because pregnancy is a ticking clock, requiring concentrated care in a relatively brief time, care delayed by administrative complexity is care denied.

Plans offered to consumers in the private sector are often difficult to comprehend; Medicaid can be even worse. The long-standing association of the Medicaid program with the stigma and complexity of welfare and AFDC offices has alienated consumers for years, as noted earlier. Similarly, providers report that the intricacy and cumbersome procedures of some private insurance plans, and of Medicaid in particular, discourage their participation in them. Even the most socially organized and well-educated consumers and providers have difficulty understanding available programs and assembling needed care. A reform plan should therefore define specific steps to simplify enrollment, participation, and payment procedures, particularly in multipayer models that, by definition, are complicated and often retain the cumbersome Medicaid program.

A more complete discussion of all these issues appears in the summary I mentioned earlier, and some five other goals are taken up in it as well.

Let me close by telling you a bit about the reaction to this modest document in the weeks since its release. As I and other workshop members have gone around paying calls on various leaders in the health care field and in the public policy domain to present this report, we have encountered two very interesting responses. The first is, "you know, we've never really thought about most of those issues." The second--more troubling, I think-- is, "all that is very interesting, but those are really minor details of implementation, to be worked out after the fact, probably through the promulgation of regulations." If the types of issues I've been outlining are really perceived outside of the maternal and child health community as being so marginal, then our work is cut out for us all -- to bring these topics up again and again, until they attain the same prominence as those currently on the table.

Thank you for the invitation to be here this morning. I'd be pleased to answer any questions.

Chairwoman **Schroeder**. Thank you. We are really pleased that you have been working so hard. And thanks for bringing the report. I am sure everybody will find it very interesting reading in the record.

Dr. Nelson, we welcome you. We are glad you joined us this morning. Your statement is in the record and the floor is yours.

STATEMENT OF RICHARD P. NELSON, M.D., PRESIDENT, ASSOCIATION OF MATERNAL AND CHILD HEALTH PROGRAMS, DIRECTOR, CHILD HEALTH SPECIALTY CLINICS, AND ASSOCIATE PROFESSOR OF PEDIATRICS, UNIVERSITY OF IOWA, IOWA CITY, IA

Dr. **Nelson**. I realize, Madam Chairwoman, that you did not offer five dollars this morning, but I do pay $126 a month for dependent coverage in my insurance policy at the university, which is a very generous policy. The university pays more than that for my own coverage. So that you need not provide five dollars.

Chairwoman **Schroeder**. I am glad that you know. But it is amazing how many Americans don't know and don't know what their employer contributes.

Dr. **Nelson**. I agree. I am Richard Nelson, from the University of Iowa. And I am currently President of the Association of Maternal and Child Health Programs. These are the public health programs supported in part by Title V of the Social Security Act for women and children, programs such as the California Children's Services that Mrs. Renshaw mentioned during her testimony.

I am pleased that we do have a chance to share some of our thoughts over a few minutes about the implications of health care reform for women, children and adolescents.

In many ways I feel my job would be done this morning in echoing some of what Ms. Brown has said about the need to consider this population in health care reform, fearing that if it is not considered we will in fact see a health care plan that discriminates against this population.

Most of the legislative proposals that have been introduced to this point in Congress focus on financing services, clearly very important, but they do not address the broader public health agenda necessary to improve health care outcomes for women and children. In my testimony I want to emphasize some aspects of that public health agenda.

Title V is the only federal program exclusively devoted to maternal and child health at this point. It is part of what we call the infrastructure or the glue which, with other public health programs, private physicians and hospitals, assures that specific health care problems are addressed.

We also coordinate with Medicaid to make certain that the technical expertise and the services of our programs facilitate the expansion of Medicaid that you have enacted in recent years for the population of women and children who are newly eligible.

State Title V programs also coordinate with and frequently administer categorical public health programs targeted to specific causes of morbidity and mortality. These programs include immunization, programs to treat children with lead poisoning, adolescents with sexually transmitted diseases, children that have been exposed to HIV, substance abuse, and the emerging problem of tuberculosis in many of our communities.

Together, all of these public health resources make up the fabric of maternal and child health services. We realize that health care reform has the potential to make major repairs and to perhaps even weave a new fabric. But we are very concerned that without attention to the specific needs of women and children, we will in fact lose the fabric that we have.

We have prepared a framework for analyzing health care reform proposals. Unlike groups that in fact have advanced a specific proposal, our framework instead is hopefully going to be helpful in analyzing specific proposals that are brought before you in the Congress to reform health care financing.

We think there are four major principles essential to this framework:

First, that there should be universal access to appropriate, comprehensive, coordinated and continuous care as a fundamental part of promoting and assuring the improved health care status for women and children.

The second principle is that public health prevention and promotion and organized health care delivery systems must complement financing mechanisms. We are basically saying we do not believe that simply providing a source of financing will assure that certain populations of women and children will receive services. We have no precedent in our country to suggest that that happens when financing is broadened.

Third, that there should be consumer and family involvement in the health care system design, implementation and monitoring. We believe that one of the problems with our system is the consumers have had too little say in how services are organized.

And finally, that the federal, state and local public health agencies should have the expertise, the mandates and critical roles to play in a variety of functions in the health care system, and that these functions need to be preserved.

This is a framework for evaluating proposals. The framework is specific to the needs of women and children. We feel this is important because historically this group is often ignored.

Now what are some of the criteria that we look for in the delivery of care to the maternal and child health population?

First, disease prevention and health promotion services must be universally available to all women, children and families. There are many examples, but to use an often cited example, we in the United States in the past year have had over 50,000 cases of measles, a completely preventable condition. Children are not being immunized because families do not have access to affordable immunization services.

Fifty thousand cases of measles results in the need for a great deal of health care, a great deal of cost, and even, unfortunately, death for some of those children.

A second component of the infrastructure is the need for publicly accountable planning and coordination of services, capacities that are often forgotten. We need to have an overview of our population so that emerging problems are addressed and that there is a capacity in our communities and in our states to mobilize resources for children and women.

A third component of the infrastructure is assuring that appropriate types of services and providers are available. This includes guidelines for distribution and mix of preventive, primary and specialty care providers.

Again, assuring that there is a source of financing does not mean that there will be resources in our most rural areas, in our innercities and in other areas of high need for health care.

Now there are a number of criteria that we think are important for personal health services for women and children. We believe that women and children should have access to health care financing regardless of age, family composition, income or employment status.

If we don't have this kind of access, there are going to be many, many children and families who don't receive the services. And we can't design a system that basically provides services for 85 or 90 percent of the population because the needs of the remaining 10 to 15 percent will undo whatever careful cost controls and other provisions are developed for the majority.

The second criterion for personal health services is that there should be payment for comprehensive and continuous personal health services that emphasize prevention and that can be provided in alternative settings, such as community-based clinics, schools, homes and other places. We know that we must be innovative in trying to bring health care to people that are at great need.

And then finally, the criterion that we think is important is that the plans must be consumer oriented with simple administrative policies and procedures, to assure greater cost efficiency. The system is simply hopelessly complex currently.

Now in my written testimony we have used this framework to analyze several of the proposals that have been introduced recently, proposals by Senator Rockefeller, Representative Stark, Representative Russo and Representative Matsui. And I am not going to spend time now verbally trying to summarize.

Each of these proposals to some extent addresses what we feel are important criteria. But in most cases the proposals simply don't consider the public health infrastructure that I have been talking about. And we feel and we hope that your committee will, among other things, consider that infrastructure as you advocate for health care reform.

We do have several specific recommendations that in closing I would like to mention quite briefly. Because the proposals currently introduced before Congress have often not fully addressed the issues, we want to make certain that you consider these issues:

Number one, that any proposal for reforming the financing of health care services should incorporate a benefit package for children, adolescents and pregnant women that at least is comparable to that included in Mr. Matsui's bill, particularly in its provisions for additional services for low income and special needs families.

Second, that legislation and financing for long term care services for children be considered, if not part of the reform at least through a separate vehicle that does not ignore long-term care issues.

Third, that there be provisions for financing and delivery of care for resident illegal alien children and pregnant women, so that they are not excluded.

Fourth, that existing public health programs be maintained at least until such time as any financing reforms are fully implemented and their impact on services and outcomes understood.

And finally, we hope that you will work with public and private health sector leaders to develop proposals for better supporting the infrastructure that I have referred to.

Our population does need protection. There is a need for legislative authority to see that resources can be mobilized when needed.

We thank you for the opportunity to talk with you this morning. We are gratified. I, again, am personally gratified to see the interest that so many of you have in this issue. And we stand ready to work with you to better address the health needs of women and children.

[Prepared statement of Richard P. Nelson follows:]

Prepared Statement of Richard P. Nelson, M.D., President, Association of Maternal and Child Health Programs, Washington, DC

HEALTH CARE REFORM: HOW DO WOMEN, CHILDREN AND TEENS FARE?

SUMMARY OF PRINCIPAL POINTS

* The Association of Maternal and Child Health Programs (AMCHP) has developed a framework to describe the essential components of a health care system that meets the needs of all women, children and adolescents, particularly those with more intensive needs due to factors such as poverty, chronic illness or disability. The framework is based on the following principles:

- Universal access to appropriate, comprehensive, coordinated, continuous care must be provided.
- Public health prevention and promotion and organized health care delivery systems must complement financing mechanisms.
- Consumer and family involvement in health care system design, implementation and monitoring is key.
- Federal, state and local public health agencies have expertise, current mandates and critical roles which must be incorporated in reform proposals.

* AMCHP's analysis of four major health care reform proposals found a focus on financing services. The proposals did not address the broader public health agenda, including the mechanisms to improve the infrastructure for health promotion, disease prevention, and planning, and to assure that services are available.

* While these major proposals include coverage for a number of preventive services, with the exception of H.R. 3393, introduced by Congressman Matsui, they limit or do not cover support services needed by low income families or children with special health care needs.

* AMCHP recommends that health care reform address the principles of this framework and include provisions for health promotion, disease prevention and service delivery systems designed to improve the health of women, children and families.

* Until reforms in the MCH infrastructure are developed and implemented, AMCHP recommends continued support for current public health programs. These programs include the Title V Maternal and Child Health program, programs targeted to specific problems such as immunization and lead poisoning, and programs for underserved areas such as community health centers.

Good morning. My name is Dr. Richard Nelson. I am the Director of the Child Health Specialty Clinics and Associate Professor of Pediatrics at the University of Iowa, and President of the Association of Maternal and Child Health Programs (AMCHP). AMCHP is a national non-profit organization representing state public health programs funded in part by Title V of the Social Security Act, or the Maternal and Child Health Services Block Grant. The mission of these programs and of AMCHP is to assure the health of all mothers, children, adolescents, and their families.

I am pleased to have the opportunity to present to the Select Committee AMCHP's views regarding health care reform and its implications for the health of women, children, and adolescents. Our members' experience in planning, delivering and monitoring health care services for this population tells us that financial barriers are not the sole factor limiting access to care or contributing to poor health status. Most of the legislative proposals before Congress focus on financing services and do not address the broader public health agenda necessary to improve health outcomes. My testimony will include a discussion of the current public system of maternal and child health services, AMCHP's framework to evaluate reform proposals, our analysis of several proposals, and recommendations.

TITLE V OF THE SOCIAL SECURITY ACT -- THE MATERNAL AND CHILD HEALTH (MCH) SERVICES BLOCK GRANT

Title V of the Social Security Act (SSA) has authorized the Maternal and Child Health (MCH) Services program since 1935. The goal of this public health program is to improve the health of all mothers and children consistent with national health objectives established by the Secretary of DHHS.

The majority of Title V funds are provided to states to assure effective MCH policies and programs, especially for: low-income families; families with limited access to care; and families with children with special health care needs due to chronic or disabling conditions. A portion of the funding is set aside at the federal level to support research, training and demonstration projects. A new set-aside program established by OBRA '89 and funded for the first time this year will support six types of projects, including those to improve provider participation in public programs, better integrate services, and increase home visiting.

Through funding to local providers or by directly operating programs, state Title V programs support the availability and accessibility of community health services especially for Medicaid insured, uninsured and underinsured families. Title V-supported programs provide prenatal care to over half a million pregnant women, or well over one-third of births to low-income women. Over two and a half million children receive Title V-supported preventive or primary health care, including immunizations, well-child exams and referral or treatment for minor illnesses. Nearly one-half million children with chronic illnesses or disabilities receive specialized health and family support services, including diagnostic, treatment and follow-up services, as well as case management or care coordination services.

State Title V programs are mandated to develop family-centered, community-based, coordinated care systems for children with special health care needs. State programs are also developing community-based networks of preventive and primary care that coordinate and integrate public and private sector resources and programs for pregnant women, mothers, infants, children and adolescents. Three-fourths of the state programs have supported local "one-stop shopping" models integrating access to Title V, the WIC food program, Medicaid and other health or social services at one site. All state Title V programs support some home visiting services, although these services are extremely limited in many states due to funding constraints.

State Title V programs conduct needs assessments to identify health problems, assess service gaps and barriers, and target resources. States develop standards to assure quality care, monitor services, and provide training and technical assistance to providers on emerging health problems and on new clinical and service approaches. State programs develop and implement health promotion and disease prevention strategies, including health education and community and environmental strategies, such as seat belts and bicycle helmets to prevent injuries.

THE PUBLIC INFRASTRUCTURE FOR MCH SERVICES

While Title V is the only federal program exclusively devoted to maternal and child health, it can be seen as the infrastructure or "glue" for a variety of other public programs that finance care, or target specific health problems or population groups. Coordination with related federal health, education and social services programs is mandated in the Title V legislation. Coordination with Medicaid has greatly intensified in recent years, with MCH programs providing the technical expertise and the service delivery systems to ensure that expanded Medicaid eligibility and benefits translate into improved access to services, and to improved health status. OBRA '89 required state MCH programs to identify and assist eligible infants and pregnant women in obtaining Medicaid. As part of these efforts, MCH programs use multi-program application forms, conduct on-site presumptive eligibility determinations, use outstationed Medicaid workers, and conduct outreach. OBRA '89 also required programs to establish toll-free information lines to help parents locate Title V and Medicaid providers. Title V programs also work with Medicaid to develop standards for EPSDT and enhanced prenatal services, provide

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case management for Medicaid clients, recruit providers, and evaluate services.

State Title V programs also coordinate with and frequently administer categorical public health programs targeted to specific causes of morbidity and mortality. These include immunizations, and programs to prevent and treat such problems as lead poisoning, STDs, HIV/AIDS, substance abuse, and tuberculosis.

Title V programs similarly coordinate with and often are directly responsible for family planning, WIC, and early intervention programs for children under age three. Title V programs support clinics in medically underserved areas, and are often the sole resource for care for low-income women and children. In areas where community and migrant health centers are also in place, Title V programs are working to assure that services are coordinated and not duplicated.

The flexibility in Title V allows for allocating resources and developing programs to complement, extend and leverage other programs, as well as private resources for health care delivery and financing.

Together, these resources make up the public infrastructure, or fabric, for MCH services. Today that fabric is wearing thin; it's been patched too many times. This quilt has holes in it through which too many women, children and families fall. Health care reform has the potential to make major repairs or perhaps to weave a new fabric. But supplying the thread of financing alone won't assure that the fabric is woven to cover women and children and protect their health.

Unless we incorporate services and activities known to improve birth outcomes, protect children and adolescents from preventable disease, injury, disability, and death, promote healthy development and improve family functioning, health care reform will not live up to its promises for women, children and adolescents.

THE MCH FRAMEWORK FOR ANALYZING HEALTH CARE REFORM PLANS

AMCHP has developed a framework to describe what it sees as the essential components of a health care system to meet the needs of all families, and particularly those with more intensive needs due to such factors as poverty or chronic illness or disability. Four major principles are central to the framework:

- Universal access to appropriate, comprehensive, coordinated, continuous care regardless of age; family composition, income or employment status; residence; citizenship status; or diagnosis or functional status should be regarded as fundamental to promoting, assuring and improving health status.

- Public health prevention and promotion and organized health care delivery systems must complement financing mechanisms to assure that community-based, family-centered health and support services are in place to promote the optimal health and well-being of women, children and families.

- Consumer and family involvement in health care system design, implementation and monitoring is key to ensuring the quality and efficacy of care.

- Federal, state and local public health agencies have expertise, current mandates and critical roles to play in assessment, policy development and assurance of health services that must be incorporated in any comprehensive health care reform agenda.

This framework is intended to be used as a guide in evaluating or developing health care reform plans and proposals at both state and national levels. The framework includes criteria for both MCH systems infrastructure and for personal health services coverage and administration. Having participated in development of the report which Sara Brown just briefed you on as well as the development of AMCHP's framework, I am pleased to note that there is much agreement within the MCH community on the major principles which must guide health care reform if it is to meet the needs of women and children. AMCHP's framework is more detailed, but consistent with that of the National Research Council.

The principles and many of the criteria of AMCHP's framework are applicable to the population and the health care system as a whole. However, much of the framework is focused on the needs of women and children who have specific health problems and needs for services. Historically, those needs have tended to be neglected unless there is specific attention to them. The scope and content of services, types of providers, and necessity for linkages with social and education services are different for children than adults. And the payoff for prevention, early intervention, and developmental and support services is higher for children. For all of these reasons, AMCHP believes that health care systems -- both infrastructure and personal health services coverage components -- must incorporate explicit provisions for women and children, including accountability through public health programs at federal, state and local levels.

MCH SYSTEMS INFRASTRUCTURE CRITERIA

AMCHP's framework includes three major components necessary for MCH systems infrastructure. First, disease prevention and health promotion services must be universally available to all women, children and their families. Accountability for these services and programs should rest with public health agencies, working jointly with community agencies and providers. These services include: ongoing surveillance of health status and services to identify problems and address them early; implementation of primary prevention strategies, such as those to eliminate lead poisoning, targeted to populations at risk; implementation of systems of comprehensive secondary prevention, such as genetics disease counseling or tracking of high-risk infants; development and implementation of public information and outreach programs designed to improve health access and utilization that are targeted to reach culturally diverse and high-risk populations; and development and implementation of comprehensive health education programs and risk reduction activities, such as school health education and service programs. These activities go well beyond the services provided by individual practitioners to their patients, and are the cornerstone to cost containment and disease prevention.

The second major component of infrastructure is publicly accountable planning, coordination and quality assurance for MCH services. Necessary activities here include data systems, needs assessment, public planning processes and reporting related to the health of women, infants and children. Coordination of public and private services and financing entails development, implementation and monitoring of agreements and arrangements that promote integration of services and maximize resources not only within the health care sector, but across education and social services. Assuring quality health care encompasses evaluation of family and provider satisfaction and the cost and outcome of services, as well as providing technical assistance, training and service demonstration funds.

The third major component of infrastructure is assuring that the appropriate types of services and providers are available. This includes guidelines for adequate distribution and mix of preventive, primary and specialty care providers, and encouraging appropriate use of non-physician providers, such as nurse midwives and practitioners, and supervised lay health workers. Support also needs to be provided for regional systems of care which assure that women and children are referred to specialty medical providers and facilities when needed. And, to fulfill a very important public health service role, the infrastructure must provide for organizing and supporting enhanced health and support services for women, children and families with special needs -- such as adolescent pregnancy and parenting support services or respite care for families of children with chronic illnesses or disabilities.

PERSONAL HEALTH CARE SERVICES COVERAGE AND ADMINISTRATION CRITERIA

AMCHP's criteria for personal health care services coverage and administration also fall into three major categories. First, all women, children and families should have access to health care financing regardless of age, family composition, income or employment status, citizenship or diagnosis or functional status. To insure such access, the plan should provide health care coverage for all family members without waiting periods; have simple forms, procedures and assistance that assure access regardless of language; and be affordable for families. It should provide, without cost-sharing, coverage for all MCH preventive services regardless of family income. Cost-sharing should not be imposed for any services for low-income families. Any premiums, deductibles, copayments or out-of-pocket expenditures should be limited, and include annual and lifetime caps to limit family liability. The plan should also provide continuation and conversion mechanisms and include coverage for catastrophic care.

The second criterion is that the plan should provide payment for a comprehensive, continuous and coordinated array of MCH personal health services that include preventive, primary, specialty and long-term care and support services, provided, as appropriate, in offices, clinics, schools, homes, and other alternative settings. AMCHP's framework specifies 25 types of services which need to be covered to promote the health of women, children and adolescents.

The final criterion for health services coverage is that plans incorporate consumer-oriented administrative policies and procedures that assure appropriate quality, utilization, efficacy, and cost efficiency. This area includes such criteria as assuring that precertification or prior authorization for specialized services is provided by appropriately credentialed and experienced MCH professionals. The criteria also address adequacy of provider reimbursement rates, simplified claims processing, and cost-control mechanisms such as incentives for preventive health services and use of managed care that is governed by MCH-specific standards.

ANALYSES OF MAJOR HEALTH CARE REFORM PROPOSALS

Using this framework, and with the assistance of health care consultants Peggy McManus, Harriette Fox, and Paul Newacheck, AMCHP analyzed three legislative proposals that typified the major approaches to health care reform as introduced by Sen. Rockefeller (S. 1177), Rep. Stark (H.R. 650) and Rep. Russo (H.R. 1300). Additionally, we analyzed the plan introduced by Rep. Matsui (H.R. 3393) because it was the only proposal developed specifically to address the needs of women and children.

The purpose of these analyses was not to endorse or critique specific proposals, but to assess the extent to which the debate and work on Capitol Hill was addressing the components of health care systems which we know to be important to improving maternal and child health. We wanted to inform and educate those involved in developing health care proposals on these necessary components. Our analysis should be finalized and available by this summer. I am pleased to be able to provide you with a preliminary summary of our findings today.

Our analysis largely confirmed what we suspected -- these prototypical legislative proposals did not devote comprehensive and systematic attention to the MCH infrastructure of disease prevention and health promotion, planning and quality assurance, and availability of providers and services needed by women, children and adolescents. Each proposal did have provisions which partially met some of our criteria, but these provisions were often incidental to and likely not intended to meet the objectives of assuring the health of women and children.

In terms of health promotion and disease prevention services, Senator Rockefeller's bill specifically provided for continuing a number of categorical public health programs, including immunizations and lead poisoning prevention, as well as health center programs in medically underserved area. Mr. Matsui's bill provided for financing outreach services that would include health promotion. While these two bills gave some attention to these public health services, none of the four proposals suggested a comprehensive approach of ongoing surveillance and needs assessment leading to prevention strategies targeted to specific at-risk populations. None suggested an agency or program such as Title V that would be accountable for health promotion and disease prevention for women and children.

Our findings regarding provisions for planning, coordinating and assuring the quality of MCH services were similar. There were some provisions in all four proposals, but none took a systematic approach. Provisions for collecting data were present but limited and largely intended for claims processing and budgeting rather than planning purposes. The bills were largely silent on development and monitoring of standards that would assure that the care needed by women, children and adolescents would be provided. Mr. Matsui's bill provides for demonstration funds to improve the delivery and quality of MCH services and Mr. Rockefeller provides for conducting outcomes research. Again, none of the bills provides a point of public accountability and MCH-specific expertise to assess needs, plan, coordinate and monitor services for women and children.

AMCHP's criteria for availability of services and providers to meet the needs of women and children are only partially addressed in the proposals. Mr. Rockefeller's proposal devotes attention to assuring an adequate distribution and mix of preventive, primary and specialty care providers, and provides for development of health centers and clinics for medically underserved populations. None of the proposals makes any provision for supporting regionalized systems of specialty care. Regionalized perinatal care systems, where women and babies at high risk of serious problems are referred to tertiary medical centers and providers equipped to meet their needs , have been credited with much of our progress in reducing infant mortality. These and similar systems must be maintained if we are to avoid backsliding.

Mr. Matsui's proposal devotes significant attention to providing family support services; home visiting, counseling and respite care are just a few examples. Mr. Russo's and Mr. Rockefeller's bills also contain some limited provisions. While all families can benefit from support services, they are particularly critical for families with more intense service needs due to such factors as poverty, adolescent pregnancy, and chronic illness or disability. Mr. Matsui's bill would provide some of these support services for poor children and pregnant women, and for children whose special health care needs would qualify them for extended benefits. The Matsui plan includes child care at service sites, translation services, care coordination, and screening follow-up. Optional services also include: therapeutic foster care, pediatric drug treatment, parent training, and in-home crisis management.

Turning to the other major component of AMCHP's Framework -- Personal Health Services Coverage and Administration -- we find a much better match with what women and children need, particularly in Mr. Matsui's bill.

All four bills aim to provide universal coverage (although the Matsui bill would do so only for children, adolescents and pregnant women), with one major exception. Except for Mr. Stark's bill, the proposals would exclude coverage of illegal alien residents. AMCHP strongly believes that access to services and coverage must be provided for illegal resident children and pregnant women if for no other reason than to minimize the costs of treatment needed when preventive and primary care is denied. All of the proposals make some provision for low-income and special needs children by eliminating any cost-sharing for low-income families, providing for continuation and conversion mechanisms, and providing catastrophic care coverage.

All of the plans are striving for uniformity in benefits, with low-income and high-risk individuals having access to some, often unspecified, level of additional benefits. Physicians services, hospital care, outpatient surgery and emergency room care would be covered in a manner similar to most health insurance plans today.

Preventive care benefits in all four plans extend far beyond what has been offered in the past by most private carriers (excluding HMOs). Specifically, well-child exams and immunizations; family planning services; prenatal and other reproductive care; genetic screening and consultation; and preventive dental care are covered in every plan. However, other preventive services, such as preconceptional care, breast and cervical cancer screening; and early intervention services for at-risk and young children are less apt to be covered or defined as specific covered benefits.

Major differences can be seen among the plans in their coverage of specific major medical and extended care services. Except for Mr. Matsui's bill, which requires a plan of care to avoid arbitrary limitations on extended care services, the bills generally do not define the amount, duration or scope of services that will or will not be reimbursed. By far, Matsui's bill offers the most generous package of benefits with the only exclusion being long-term home health services and long-term skilled nursing facility services. Allied health services would be covered as long as they are authorized under state law and consistent with a plan of care developed in consultation with the attending primary care physician.

Mr. Russo's bill also calls for a generous package of extended care benefits with prior certification requirements for certain home and community-based services. Licensed allied health services are covered, as authorized under state law. Mental health and substance abuse benefits are covered, but limited. A wide range of additional services, such as care coordination and home visiting services, could be covered at the Secretary's discretion, but are not specifically defined in this plan.

Mr. Rockefeller's bill attempts to offer a basic health services package with limited extended care benefits. Mental health and substance abuse inpatient and outpatient benefits are covered, but restricted. Care coordination, prescription drugs, allied health services, assistive devices, therapeutic day care, hospice care, and long-term home and community care are not covered. Under Mr. Rockefeller's proposal, preventive benefits include EPSDT services, but it is unclear if the definition used in the bill is consistent with current EPSDT law, which allows for comprehensive coverage of extended care services.

Mr. Stark's bill covers Parts A & B of Medicare plus additional preventive benefits, pregnancy-related services, prescription drugs, and eyeglasses and hearing aids. However, among allied health service providers, only occupational and physical therapists' services are covered. Care coordination, home visiting, therapeutic day care, and long-term home and community care are not covered in this primarily Medicare plan.

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Simple comparisons of benefits, without considering cost-sharing requirements, may yield inappropriate conclusions regarding the "generosity" of benefits. Service coverage in combination with cost-sharing requirements will have differing effects on children with and without special health care needs. For example, a healthy child covered by Mr. Russo's or Mr. Stark's plan may fare very well because they mainly require preventive and primary health services, which are covered with little or no deductible or co-payments. Mr. Matsui's and Mr. Rockefeller's bills have greater cost-sharing requirements. A child with special needs, on the other hand, may have greater financial protection under Matsui's and Rockefeller's plans because of the scope of covered benefits and the cap on annual out-of-pocket expenditures.

Finally, the four proposals are uneven in their provisions for consumer-oriented policies that assure appropriate utilization, quality, and cost-efficiency. The bills do not specifically address policies that would assure appropriate duration, scope, frequency and setting for covered services, such as prior authorization and precertification for intensive services, or consumer-preferences for provider types and settings.

In terms of payment procedures, all of the bills would provide for simplified claims processing. Mr. Matsui and Mr. Rockefeller provide for formal appeals processes for providers and families. All bills but Mr. Matsui's would require providers to accept payments without balance billing.

All bills devote some attention to assuring that payment rates are adequate to assure provider participation, and all contain some measures designed to control costs. Mr. Matsui includes incentives for use of preventive health services and a range of providers and settings.

In summary, AMCHP's analysis of four major legislative proposals for health care reform confirmed that Congressional policy makers have largely confined their focus to the financing of health care. Uneven and marginal attention has been paid to reforming systems to assure that health services are available and designed to meet women's and children's needs and to improve health outcomes. Provisions for health systems infrastructure are particularly critical to women and children with more extensive needs for health and related support services due to such factors as poverty and chronic illness or disability.

Even when we focus on the financing of personal health services for women and, children, and adolescents, all but Mr. Matsui's bill omit, limit, or fail to specify the inclusion of some services needed by women and children. These omissions are of particular importance for women and children whose specific needs have historically been neglected by the general medical care system.

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RECOMMENDATIONS

AMCHP and many of our colleagues in the public health and women and children's services arenas firmly believe that specific attention must be devoted to policies and resources that will assure that families have access to and utilize services that will promote their children's health. Improved financing of care is a necessary but not sufficient step toward that goal. To comprehensively reform health care, explicit attention must be devoted to the infrastructure of health services, and to financing of services for those with special needs. AMCHP today offers the following preliminary recommendations for the Committee's consideration:

1. Any proposal for reforming the financing of health care services should incorporate a benefit package for children, adolescents and pregnant women that is at least comparable to that included in Mr. Matsui's bill, particularly in its provisions for additional services for low-income and special needs families.

2. Legislation and financing for long-term care services for children with severe and/or multiple disabilities needs to be developed either as part of reform to assure universal access or through a separate vehicle addressing long-term care. Such legislation must give explicit attention to meeting children's and adolescents' and their families' needs, which differ in some respects from those of adult disabled and elderly populations.

3. Provisions for financing and delivery of care for resident illegal alien children and pregnant women should be included in health care reform.

4. All existing public health programs should be maintained with adequate funding at least until such time as any financing reforms are fully implemented and their impact on services and outcomes assessed, or until comprehensive reform proposals that include provisions for health system infrastructure are enacted.

5. Last, but most ideally, Congressional policy makers should work with public and private sector health care leaders to develop specific proposals for reforming and better supporting the health services infrastructure. Legislative authority and resources need to be dedicated to those services and activities that will not be financed through insurance coverage mechanisms. Policies and financial support are needed for personal health services and health systems infrastructure to mend our fragmented system.

Through development of its framework and analyses, AMCHP has taken steps to articulate what we as public health experts believe are the necessary components of health services infrastructure and financing needed to assure the health of women and children. We are also beginning a process to outline our vision of the future role of the Title V program in a health care environment which provides universal financing. We have been gratified to share our efforts to date with you today, and stand ready to work with you to better address the health of women and children in the future.

MATERNAL AND CHILD HEALTH FRAMEWORK

FOR

ANALYZING HEALTH CARE REFORM PLANS

Association of Maternal and Child Health Programs

MATERNAL AND CHILD HEALTH FRAMEWORK FOR ANALYZING HEALTH CARE REFORM PLANS

PREAMBLE

National attention currently is focused on ways to better support children and families, and to assure access to health care for all. The Association of Maternal and Child Health Programs (AMCHP), a national nonprofit organization which brings together state public health programs addressing the needs of women in their reproductive years, children, youth, and families, shares both these goals. As public health experts with a mandate to assure the health of all mothers and children, AMCHP members are particularly concerned about the intersection of the goals of financing and comprehensive services.

There has been growing recognition that the piecemeal, inadequately financed, and often conflicting or overlapping programs and policies currently in place are not sufficient to achieve significant progress in reaching either of these goals. A large number of proposals to assure access to health care have been advanced: some focus only on children and pregnant women, some encompass the entire population, and some of the latter give priority to women and children in phased-in approaches. While all of these proposals aim to improve the financing of health care, they vary greatly in provisions for assuring that care is available, accessible, comprehensive, of high quality, and cost-effective, particularly in promoting the health of women and children.

As the national debate evolves about alternative approaches to resolving the health care financing dilemma, there appears to be a growing awareness that financing reform alone will not be sufficient to ensure that the Year 2000 health objectives for the nation are achieved. The organization, administration and delivery of health services must be part of the deliberations if we are truly to achieve health care reform. These considerations are particularly important to maternal and child health status. Health care will be incomplete if we fail to address services and activities known to improve birth outcomes, protect children and youth from preventable disease, disability and death, promote healthy development, and improve family functioning. These services are important to the health of all families, and must be responsive to the special needs of children and youth with chronic illness and disabilities and their families.

MCH Principles For Health Care Reform

The Association of Maternal and Child Health Programs has developed the following framework to describe what it believes are the essential components of service delivery and financing systems needed to meet the needs of all families. Four major principles are central to the framework:

- Universal access to appropriate, comprehensive, coordinated, continuous care regardless of age, family composition, income or employment status, residence, citizenship status, or diagnosis or functional status should be regarded as fundamental to promoting, assuring and improving health status.

- Public health prevention and promotion and organized health care delivery systems must complement financing mechanisms to assure that community-based, family-centered health and support services are in place to promote the optimal health and well-being of women, children and families.

- Consumer and family involvement in health care system design, implementation and monitoring is key to ensuring the quality and efficacy of care.

- Federal, state and local public health agencies have expertise, current mandates and critical roles to play in assessment, policy development and assurance of health services that must be incorporated in any comprehensive health care reform agenda.

The Role Of Public Agencies

This framework does not identify a specific agency or program to carry out functions related to public health and personal health service systems infrastructure, organization, or administration. The AMCHP concurs, however, with the Institute of Medicine that the critical roles of assessment, policy development and assurance must be carried out by public health agencies at federal, state and local levels if the health care system is to function well. Further, recognizing that women and children have special needs which require specific expertise and an accountable locus of public responsibility, there will continue to be a need for mandates, financing and an infrastructure to ensure ongoing attention to their needs.

The AMCHP believes that the historical mission and current mandates of the Title V Maternal and Child Health Services Block Grant program are consistent with the public health agency roles that are necessary in health care system reform. Roles currently implemented by state Maternal and Child Health programs which are consistent with those in the framework include: monitoring health status and services, and developing plans, policies and programs to improve them; providing financial support, technical assistance, training and other supports to facilitate development and maintenance of systems of coordinated, community-based comprehensive care; and collecting, analyzing and reporting data to assure services quality and accountability.

Title V has long served as a residual financer of health care, a role that is likely to diminish considerably, although not entirely, when significant reform in health care financing occurs. It is likely that MCH professional expertise and financial resources will continue to be needed to support services availability and an infrastructure of comprehensive care integrating social, education and support services with medical care. Such resources also will be needed to develop, pilot and evaluate new intervention and systems strategies.

State Title V programs played an important role in implementing Medicaid expansions by consulting in development of and administering benefit packages; recruiting and certifying providers to serve increased numbers of women and children; and by coordinating care for families with multiple and special needs. 1989 amendments to Title V reinforced the role of the MCH program in assuring preventive, primary and specialty health and support services for all mothers and children, and explicitly stated the program role in providing, promoting and facilitating the development of community-based, family-centered, coordinated systems of care. The AMCHP believes that MCH programs' expertise will continue to be needed under universal financing to assure that increased access results in improved health outcomes.

This framework has been developed by the Association for use by state and national policymakers, program administrators and advocates in evaluating or developing health care reform plans and proposals. The Association has not made recommendations for financing mechanisms; the AMCHP framework focuses instead on needed MCH services and system capacities.

FRAMEWORK FOR MATERNAL AND CHILD HEALTH (MCH) SYSTEMS INFRASTRUCTURE

I. **Disease prevention and health promotion services are universally available to women, children and their families through public health activities. Accountability for developing, coordinating, monitoring and evaluating these services and programs rests with public health agencies. Joint planning and implementation is carried out with community-level public and private agencies, organizations, and providers, and with consumers and families. These services and activities should include:**

   A. Ongoing surveillance of health status and services;

   B. Implementation of primary prevention strategies (e.g., relative to injury, lead poisoning, AIDS, chronic disease, immunization, etc.) with targeting to populations at risk;

   C. Implementation of systems of comprehensive secondary prevention services (including, for example, newborn screening; genetics disease screening and counseling; regionalized systems of perinatal and neonatal high-risk services; high-risk tracking and follow-up services; early intervention services; and infectious disease control);

   D. Development and implementation of public information and outreach programs designed to improve health care access and utilization, with targeting to reach culturally diverse as well as high-risk populations; and

   E. Development and implementation of comprehensive health education programs and risk reduction activities (addressing family life; parenting skills; substance abuse; AIDS; family planning; preconceptional care; etc.) available throughout the life span in age-appropriate settings.

2. **Public accountability for MCH systems planning, quality assurance, and coordination is defined in public health statutes to include:**

A. MCH Data Systems Design and Management

- Establishing information systems that allow reporting of uniform data across multiple service providers, payers and programs; and

- Producing data useful for national, state and community assessment and monitoring of health status, service quality (process, content, outcome), utilization, and costs.

B. Assignment of responsibility to an identified unit of the health agency, directed and staffed by individuals with public MCH expertise, for data-based needs assessment and public planning processes which include racially and culturally representative consumer-family and provider participation, and for reporting related to the health of women, children and families.

C. Coordination of public and private MCH services and financing through the designated MCH unit addressing:

- Development of (or adoption of national) uniform definitions of benefits and services across service sectors;

- Development and adoption of policies, procedures and service delivery mechanisms implemented at state and community levels that facilitate access to programs and services (including, for example, common forms, co-location of intake and/or service delivery, etc.);

- Development of state and local interagency agreements delineating service provision, coordination, financing, program planning, and administrative roles; and

- Effective use of available public (federal, state and local) and private financial resources to maximize client access to care and expand the scope of available health and support services.

D. Responsibility for MCH services quality assurance through the MCH unit assuring that:

- Both publicly and privately provided or financed health services are delivered consistent with nationally recognized professional standards of care;

- As needed, standards of care for enhanced health and support services (e.g., children with special health care needs, high-risk perinatal, etc.) are developed and promulgated;

- Providers meet credentialing requirements;

- Service provision is monitored on an ongoing basis through structured review processes;

- Mechanisms exist for regular review and revision of standards to reflect changes in technology and/or state-of-the-art practices;

- Monitoring includes evaluation of family/consumer satisfaction, provider satisfaction, delivery process, cost, and health status outcomes;

- Practices and/or programs determined ineffective in contributing to desired health outcomes are discontinued;

- Mechanisms exist for dissemination of information on best practices; and

- Adequate funds and other resources are directed toward service demonstrations and education and training for state and local MCH service providers.

3. **Provider/Service availability is assured by the MCH unit in collaboration with all state and community-level private and public sector providers, agencies and payers to:**

A. Develop guidelines for adequate distribution and mix of preventive, primary and specialty service providers needed within defined geographic areas (at community, regional and state levels);

B. Encourage appropriate use of mid-level practitioners and alternative providers such as appropriately skilled and supervised lay health workers;

C. Develop requirements or incentives to assure full participation and equitable geographic distribution of service providers offering primary, specialty and subspecialty care;

D. Support, through policies, training and financial support as necessary, regionalized specialty services;

E. Develop mechanisms to assist families in using services (e.g., transportation, support for medically related days); and to:

F. Organize and support, as needed, basic and enhanced health and family support services particularly for populations of women, children and youth with special needs (e.g., parent training, respite care, home visiting, [illegible] appropriate assessment of risk, adolescent pregnancy and parenting services, etc.).

CRITERIA FOR PERSONAL HEALTH SERVICES COVERAGE AND ADMINISTRATION

1. **All women, children and families have access to health care financing regardless of age; family composition, income, or employment status; citizenship; or diagnosis or functional status. To ensure access, the plan/program:**

   A. Provides health care coverage for all members of the family unit without waiting periods. Families are defined to include an individual, the individual's spouse, and children of the individual and spouse, including foster children and children in the process of adoption;

   B. Has simple application forms, enrollment procedures and assistance that assure access regardless of language used and include interpreter and translation services;

   C. Is affordable for families. Provides, without cost-sharing, coverage for all MCH preventive services regardless of family income. Cost-sharing is not imposed for any services for low-income families;

   D. Establishes any cost-sharing at graduated levels relative to income and resources, and consistent regardless of risk. Limits are applied to any premiums, deductibles, copayments and out-of-pocket expenditures, and include annual and lifetime caps to limit family liability;

   E. Provides continuation and conversion mechanisms related to age, diagnosis or functional status; and changes in employment or employer plans; and

   F. Includes coverage for catastrophic care.

2. **The plan provides payment for a comprehensive, continuous and coordinated array of MCH personal health services that includes preventive, primary, specialty and long-term care and support services, provided, as appropriate, in offices, clinics, schools, homes, and other alternative settings. Covered MCH services include:**

   A. Reproductive health care, including routine exams, breast and cervical cancer screening, sexually transmitted disease screening/treatment, etc.;

   B. Family planning, including education, contraceptive care, pregnancy testing and counseling;

   C. Preconceptional care, including risk assessment (with genetic screening and consultation as appropriate), health promotion and intervention to reduce risks;

   D. Risk appropriate prenatal care in accordance with standards of the American College of Obstetricians and Gynecologists;

   E. Well-child examinations which include all appropriate screening services and immunizations according to standards of the American Academy of Pediatrics;

   F. Developmentally appropriate anticipatory guidance (client and/or parent education);

   G. Preventive dental care, including exam, prophylaxis, and sealants as appropriate;

   H. Outpatient diagnosis, evaluation, and treatment of suspected health or developmental problems;

   I. Home visiting services to provide enhanced risk-appropriate maternal and child health assessment, education and support;

   J. Care coordination (case management), including designation of a "medical home" or primary care provider;

   K. Risk-appropriate perinatal and neonatal care, including transfer to special perinatal centers for mother and/or infant;

   L. Outpatient provider services for diagnosis and treatment of acute or episodic health conditions;

   M. Outpatient surgery;

   N. Emergency room care;

   O. Prescription drugs;

   P. Optical, hearing devices;

   Q. Curative dental care;

   R. Inpatient evaluation of suspected health or developmental problems;

   S. Inpatient care and treatment (including surgery and post-operative care);

   T. Allied health and related services such as social work, nutrition; occupational, physical, speech, language and respiratory therapies; audiology;

   U. Mental health care (outpatient and inpatient);

   V. Alcoholism and drug addiction treatment services (outpatient and inpatient);

   W. Early Intervention services provided in age-appropriate community settings;

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X. Parent (caregiver) training as appropriate and necessary to support child health and developmental services for high-risk children; and

Y. Specialty and support services for chronic health and developmental impairments and conditions, including habilitative medical equipment, assistive devices (for mobility, communication and activities of daily living) and supplies (including special formulae, etc.); therapeutic day care; hospice care; and long-term chronic care (home-based and community congregate settings).

3. The plan incorporates consumer-oriented administrative policies and procedures that assure appropriate quality, utilization, efficiency and cost-efficiency.

A. Appropriate duration, scope, frequency of and settings for provision of covered secondary and tertiary level services are determined through precertification or prior authorization performed by appropriately credentialed and MCH-experienced health professionals:

- Precertification decision-making is guided by standards of care or protocols for acute, recurring and chronic illness and health impairments;
- Consultations and second opinions are paid for under the plan upon consumer, primary care provider or authorization review personnel request; and
- Mechanisms exist to obtain information on and include consideration of individual client (family) perspectives regarding service needs and service delivery (provider and/or setting) preferences.

B. Procedures are implemented to reduce family and provider burden in forms completion and to expedite payment to clients and/or providers, which include:

- Simple claims processing forms and procedures;
- Coordination of claims conducted by insurers or providers, and not families;
- Requirements that providers accept assignment of benefits other than family deductible and copayment amounts; and
- Formal appeals processes applicable to beneficiaries and providers.

C. Provider payment rates and mechanisms assure adequate participation by the full range of needed MCH health professions through:

- Adequate reimbursement levels to assure that all health clinicians (including mid-level practitioners, specialists and subspecialists) and facilities participate as providers under the plan;
- Appropriate reimbursement schedules to assure that no providers are required to bear a disproportionate share of costs; and
- Timely and efficient provider payments, with provider access to consultation and assistance in implementing the billing process.

D. Cost controls are established through mechanisms such as:

- Implementation of incentives for provision and utilization of MCH preventive health services;
- Use of a range of MCH health care providers and service delivery site alternatives;
- Use of managed care arrangements in conjunction with MCH provider and service quality controls and monitoring;
- Prohibitions regarding balance billing; and
- Established limits on the percentage of costs for administration.

The MCH Framework for Analyzing Health Care Reform Plans was developed by a special subcommittee of the AMCHP's Finance and Children with Special Health Care Needs Committees and was approved by the Association's Executive Council in November, 1991. Assistance in development and editing of the document was provided by Holly Grason, M.A., Deputy Director. Consultation was provided by New England SERVE. Development of this document was supported in part through a cooperative agreement with the Maternal and Child Health Bureau, Department of Health and Human Services, No. MCU 116046-01. For information or additional copies, contact:

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Chairwoman **Schroeder**. Thank you again, Dr. Nelson. And I am sure your written testimony analyzing the different bills out in front of us is going to be very helpful to my colleagues as we look at that.

We now move along to Mr. Haislmaier. We welcome you. Your statement is in the record and the floor is yours.

STATEMENT OF EDMUND F. HAISLMAIER, POLICY ANALYST, FOR HEALTH CARE ISSUES, THE HERITAGE FOUNDATION, WASHINGTON, DC

Mr. **Haislmaier**. Yes. I am afraid that I will need to leave fairly soon today, as I mentioned to the staff. Unfortunately, I have to catch a flight.

Chairwoman **Schroeder**. Sure.

Mr. **Haislmaier**. Since you already have my statement, I will depart somewhat from what I have submitted, and will address some of the problems that were brought up in the first panel here. In my statement I did not deal much with the issue of insurance reform, and I would like to elaborate here on that a little bit.

I would start with the observation that when you see everyone doing the wrong thing in a given situation, it is not that all the people involved are bad, it is probably that the rules are bad.

In other words, when we see hospitals overcharging, or insurers dumping sick people or things like that, it is not that all insurers are bad or all hospitals are bad, or all doctors are bad. It is that the incentive structure is often what is wrong.

The analogy I use is, imagine if in football the rules said that instead of getting a penalty for personal fouls, the team that injured opposing players would get extra points. You would have mayhem on the playing field and it wouldn't do any good to lecture or berate the players, or the coaches or the fans. You would need to change the rules.

The proposal that we at the Heritage Foundation have come up with for a consumer choice health system is designed to change the rules, to create a more efficient system of financing health care and a more compassionate system that covers everyone.

Very briefly, the key points of our proposal are: First, employers would be required to convert into cash wages the money now spent on health benefits. Second, the Federal Government would then provide individuals and families directly with new tax credits for money spent on all health expenses. And I stress all health expenses, not just the purchase of health insurance but the purchase of medical care out-of-pocket as well as the purchase of insurance.

Third, the size of the tax credits would vary depending on the income and health expenses of the family. So for example, the families we had here this morning that have larger health expenses relative to their income than, say, somebody else with the same income, would get more generous assistance in the form of larger tax credits. These tax credits would even be refundable.

Fourth, the tax credits would be funded by gradually eliminating the present tax exclusion for employer-provided insurance, which is what supports the existing system. This means that the reforms would be budget neutral. It is not absolutely necessary for them to be budget neutral. We have suggested this because we think budget neutrality is attractive, given the current climate in Congress.

If someone was to say, "You are not providing enough help to this particular group, they need more money," you could make our proposal more generous by adding more money. Of course you can come up with more money either through higher taxes or budget cuts. We would argue for budget cuts elsewhere. But if you can come up with more money, it can certainly be blended into our proposed system.

Fifth, all heads of households would be required to purchase a basic catastrophic health insurance policy covering themselves and their family members.

And sixth, health insurance regulations would be changed to give policyholder the right to renew their policies and to eliminate the practice of experience rating renewal premiums.

I am personally familiar with some of the problems that were discussed here this morning. I was uninsured for five years after I got out of school. Like the majority of uninsured people, I was fortunate that I did not have a serious illness. But I took a very big risk because the jobs that I worked in, including political campaigns, simply didn't provide health insurance.

I also have a brother whose family has been faced with many of the same problems as the families on the panel this morning, due to the illness of a child and his attempt to go from being employed by a company to being self employed. At one point he was forced to go back to being employed by a company which offered health benefits. So I am very familiar with these problems.

I would briefly make a couple of points here about insurance that were not in my written testimony. Indeed I am in the process of writing a longer piece on the subject.

The first point I would make is that there really are limits to what any kind of an employment-based health insurance system can achieve. Therefore, we should not be surprised that there are problems with an employment-based system.

To start with, there are always people on the margins of the work force. They are workers who are low income, or self employed, or part time, or seasonal laborers. There are always these people on the margins of the work force. Of course, there also are unemployed people.

Therefore, if we tie health care to employment in any way, shape or form, we are buying into a whole set of additional problems right off the bat. That is why I see the only real reforms as being ones that move away from an employment-based system, either in the direction I have suggested of an individual consumer choice system or, quite honestly, in the direction of a government-run national system. I just do not see that we can make much progress continuing with the existing employment-based system.

The next point I would make is that we do not have a health insurance system in this country. What we really have is a prepayment of medical care system.

Now in some cases that makes sense. But in the case of major illness, it does not make sense to have prepayment of medical care.

Insurance in any form is the acceptance and management of risks. So when we see health insurers, unlike insurers in every other area, avoiding risks instead of accepting risks, I think that should be a flag signaling that there are serious problems with the way the system works.

Finally, insurance is certainty. That is the commodity that insurers are selling. The problem is that today we are not getting certainty out of our health insurance. That is another flag, I think, that should tell us we really don't have true health insurance, but rather prepayment of medical care.

What would a true health insurance system look like? It would look like your life insurance. You would be given a premium based on the expected risk, not just for the short term of a year—and this is where many of the problems come today—but over a long period of time.

If you think about it, all policyholders of a life insurer will eventually die. So it is not a question of whether a loss will occur. It is a question of when. Therefore, life insurers spread risk over time.

I think the same holds true in health care as well. We will all eventually become sick. Therefore, health insurance should look to spread risks over time, not just among a group on a short-term basis.

Under a true health insurance system, people would initially be charged a premium to match their risks. But then they would have a right to renew their policy. They could not be dropped by the insurer. Furthermore, the renewal premium they would be charged in subsequent years would be based on the total claims experience of all the people covered by the insurer and not just the experience of each particular individual.

I believe that this is the kind of certainty that Americans are looking for, together with a more portable system of insurance. I also think, as I mentioned in my testimony, that a consumer-driven system will offer powerful incentives for the purchase and use of preventive care services and will turn managed care into a system for helping people stay healthy, as opposed to what it has now become, as Ms. Brown pointed out, a demand control tool.

Thank you very much.

[Prepared statement of Edmund F. Haislmaier follows:]

PREPARED STATEMENT OF EDMUND F. HAISLMAIER, POLICY ANALYST FOR HEALTH CARE ISSUES, THE HERITAGE FOUNDATION, WASHINGTON, DC

Madam Chairwoman, Members of the Committee. My name is Edmund Haislmaier and I am the Policy Analyst for Health Care Issues at The Heritage Foundation. I appreciate the opportunity to testify before you today on the issue of health care reform, particularly in relation to its likely effects on women, children and families. The following statement represents my own views and should not be construed as representing any official position of The Heritage Foundation.

Practically everyone agrees that America's present health system costs too much and denies needed care to too many people, and that both problems are getting worse. But, beyond this general agreement, opinions diverge sharply over the precise factors responsible for the system's problems and the best reforms to institute.

Congress is now considering a variety of health care reform proposals. Although these proposals may seem to differ widely, they can in fact be segregated into three basic categories.

REFORM OPTIONS

First, are proposals which aim to build on the employment based insurance system which currently covers the majority of working Americans and their families by plugging existing coverage gaps. They are often characterized as "play or pay" or "employer mandate" proposals. These terms refer to their common, basic feature of requiring employers to either purchase a required minimum package of private health insurance coverage for their workers and dependents, or pay a payroll tax to fund similar coverage through a public plan.

Second, are proposals to replace the current system with some form of "single payer" or "national health insurance" model. In these proposals, a government agency of some form is the sole payer for health services provided to all Americans, and imposes budgets, price controls, expenditure limits and other direct constraints on health care providers.

Third, are "consumer choice" or "tax reform" proposals. They would construct a universal system based on the principles of consumer choice and market competition. To accomplish this, they would change current health care tax policy so as to empower consumers by giving them control over the their own health care spending, while also providing more generous, direct assistance to the needy and disadvantaged. Health care providers and insurers would, in turn, be forced by market competition to respond to consumer needs and demands. The Heritage Foundation has advanced such a proposal.

In the balance of this testimony, I will first offer my analysis of the underlying causes of the health care problems we now face. I will then describe the basic features of The Heritage Foundation's consumer choice health care reform proposal and how it would address those problems. Finally, I will offer an analysis of the likely effects of our proposal, particularly as it would effect women and children, together with some observations concerning the other two basic approaches to health care reform.

SOURCE OF THE PROBLEMS IN THE HEALTH SYSTEM

Much of the present health care debated centers on the high, and constantly escalating, cost of health care. But I do not believe that health care costs, per se, are the real problem. The real problem is that health care in this country today is a bad value. In other words, as individuals and as a nation we are spending a great deal on health care, but we do not believe we are getting our money's worth. There is a very important distinction between cost and value. It is possible for something to cost a lot and still be a good value for the money spent. It is also possible for a lower cost item to be a good value.

In the case of our health system, it is not that the goods and services we receive are necessarily inferior or poor quality, it is that they are not worth the price we are paying. Consequently, we complain about health care costs when our real concern should be value.

The first thing I believe Americans want in health care is a more efficient system. In other words, a system that gives them better value for money. The problem with government-financed or regulated health systems, as proposed in "single-payer" or "play or pay" schemes, is that, ultimately, they can only offer to reduce costs through a strategy of "less for less" -- less spending in exchange for less benefits. But better value implies a "more for less" strategy -- getting more benefits while spending less. Another term for a "more for less" strategy is increased productivity. But governments cannot legislate productivity increases. They can only be produced by sound, competitive markets in which consumers are rewarded with cash in their pockets for choosing better value for money, and providers are rewarded with more business for offering better value for money.

The second thing I believe Americans want in health care is a compassionate system. In other words, a system that provides the same care and benefits to the poor and the sick as it does to the healthy and wealthy.

I would argue that government's role in health care should be first to create a sound, competitive market that offers better value for money. Next, government should take steps to increase the purchasing power of the disadvantaged so they can buy the medical care and health insurance they need, thus creating a universal and compassionate system.

The present health system is clearly neither efficient nor compassionate. The principal reason is the current tax treatment of health benefits.

Money spent by an employer on a worker's health insurance is really part of the worker's wages. But under federal tax law, it is not counted as taxable income to the worker, who thus avoids paying any federal income or payroll taxes, or state income taxes, on it. This policy effectively offers Americans very generous tax relief on their medical expenses, but only on two conditions. First, they must purchase their medical care through health insurance, and second, they must purchase their health insurance through their employer.

In many cases, however, it would be more desirable or cost effective to purchase low-cost or routine medical care directly out-of-pocket, or to buy a health insurance plan other than the one offered by the employer. But workers who choose either of these options are heavily penalized by losing tax relief for their medical expenses. Because they lose more in tax relief than they gain in savings, workers often forgo these cost effective options.

Furthermore, these tax rules encourage workers to think they are buying health care with someone else's money -- like an expense account lunch. As noted, the money spent on a worker's employer-sponsored health benefits reduces the worker's cash wages. But, few workers actually know how much is being spent, and even fewer have any direct say in how it is spent. Indeed, the present employer-sponsored health insurance system is all but designed to ensure that workers remain ignorant of the true costs of their health benefits. It also virtually guarantees that consumers will not have the information they need, in a form they can use, to accurately determine value for money in medical care.

The results are predictable. Because workers see little or no direct cost attached to their increased consumption of health services, they are encouraged to demand more, even when the costs far outweigh the likely benefits. Similarly, workers see little direct cost to them when providers increase the prices they charge, so workers are encouraged to ignore price hikes. Conversely, a worker with employer-sponsored health insurance who is cost conscious -- seeking out providers who offer good quality at good prices -- is not rewarded since it is the employer who pockets the savings. In sum, Americans have little incentive to consider relative price differences, or costs versus benefits, when making health care purchasing decisions.

At the same time, providers who offer good quality at lower prices are not rewarded with a larger volume of business, and thus more income, since their patients, who are directly paying little or nothing of the bill, or even their insurance, rarely notice. Instead, providers who dispense more services, regardless of their benefit, or charge higher prices, get the higher incomes.

Not only does the present system penalize efficiency and reward inefficiency, it also is highly inequitable. The greatest tax relief for health care goes to those who need it least -- well-paid workers with generous health benefit plans. But those without employer-sponsored coverage, who most need help -- namely, self-employed, low wage, or part-time workers, or employees of small business -- receive little or no tax relief for their medical care and insurance.

For example, the present tax exclusion for employer-sponsored health insurance provides Americans with approximately $67 billion a year in tax relief. Yet of that amount, $38 billion, or 57 percent, goes to families with annual incomes of $50,000 or more. Only $4 billion, or 6 percent, goes to families with annual incomes of $20,000 or less.

CONSUMER CHOICE HEALTH CARE REFORM

The Heritage Foundation's consumer choice health reform proposal would change these tax rules to give consumers direct control over health spending and create positive new incentives for both consumers and providers. It also would target government assistance to those in greatest need. The proposal essentially consists of six basic changes.

1) Employers would be required to convert money now spent on employee health benefits into cash wages in the first year. But beyond that, future wage rates would be subject to normal labor-management negotiations. Employers would further be required to deduct insurance premiums from employee paychecks and send the premiums to the insurers chosen by their workers. Employers could also, voluntarily, serve as brokers helping workers choose insurance plans, or arranging wholesale purchase discounts from insurers and providers.

2) The federal government would provide individuals and families with new tax credits for money spent both on health insurance and on out-of-pocket medical care, regardless of where it is purchased. Taxpayers would get the same tax relief for purchasing health insurance through their employer, or through a union, farm bureau, church, fraternal organization, professional society or other group, or on their own. Furthermore, individuals and families would get the same tax relief for a dollar spent buying medical care directly as they would for a dollar spent on purchasing health insurance. The credits would also be blended into the existing tax withholding system, so taxpayers would not need to wait until the end of the year to get the money back from the government.

3) The size of the new tax credits would vary depending on the size of a given household's health expenses relative to its income, thus providing more tax relief to those with lower-incomes and/or higher health-care costs. The credits would also be refundable. The Heritage Foundation proposal suggests several tax credit structures.

One version would give taxpayers a 20 percent credit for all health expenses below 10 percent of gross income. The credit would then rise to 45 percent for health expenses between 10 and 20 percent of income and to 65 percent for health expenses above 20 percent of income.

Another version would provide an initial, voucher-like tax credit of $220 per family member toward purchasing basic, catastrophic health insurance. An additional 20 percent tax credit would apply to health insurance premiums above the initial amount of $220 per family member and all money for out-of-pocket medical bills.

4) The new tax credits would be funded by gradually eliminating the present tax exclusion for employer-sponsored health benefits and other existing health-care tax breaks. Americans would receive the same total health-care tax relief, but in the form of tax credits instead of a tax exclusion. This also means the reforms will be budget neutral.

5) All heads of households would be required to purchase a basic, catastrophic health insurance policy covering themselves and their family members. This requirement is needed because a small minority of irresponsible individuals might decline to purchase insurance, and then expect the rest of society to pay for their treatment if they suffer a medical catastrophe.

Employers would be required to report to a state agency those workers who refused to choose an insurance plan or show proof of coverage under a policy paid by another family member. The state would then enroll those workers and their dependents in Medicaid, or another plan chosen by the state, and assess them premiums based on their ability to pay.

6) Health insurance regulations would be changed to give policyholders the right to renew their policies and to eliminate the practice of "experience rating" renewal premiums. Policyholders would thus have the same protection in their health insurance that they now have in their life insurance. Their insurer could not cancel or refuse to renew their coverage, or hit them with exorbitant premium increases, if they became sick. All policyholders covered by a given insurer would see the same percentage increase or decrease in their annual renewal premiums, based on the percentage increase or decrease in total claims paid by the insurer.

In addition to these major steps, there would be some temporary regulations during the transition to the new system. The regulations would guarantee that all Americans now covered by employer-sponsored group health insurance would have their benefits converted into portable individual or family policies with premiums no more than 25 percent higher than what their employer now pays. This would prevent insurers from dropping coverage on those who are now insured but who are sick or high risk, or hitting them with exorbitant premium increases.

Current government health programs, such as those for the non-working poor and the elderly, would be retained, though some modifications of those programs should be considered as well. But as the majority of Americans became better health care consumers, costs would be brought under control throughout the system, allowing government programs to expand help for those in greatest need.

BENEFITS OF A CONSUMER CHOICE HEALTH SYSTEM

A consumer choice health system of this kind would provide all Americans, including women and children, with better value medical care and health insurance, and better access to care. Individuals and families would make their own decisions about health care based on their own needs and preferences. Their purchasing decisions would not be biased by the tax code, since the new tax credits would apply equally to insurance premiums and out-of-pocket health spending.

Some likely will prefer to pay for more of their routine medical care out-of-pocket and buy no-frills health insurance at a savings of hundreds, or even thousands, of dollars a year on premiums. Others will likely prefer more comprehensive coverage. For them, a managed care plan, such as an HMO, would be able to offer significant savings by steering them to more efficient providers.

Also, many consumers will likely find that they could get additional wholesale purchasing discounts on insurance by buying through a group whose advice they trusted. But, no longer would tax benefits go to only one kind of group purchasing arrangement -- namely, employer-sponsored groups.

Regardless of their specific choices, all Americans would have a strong incentive to buy better value medical care and health insurance, since they would pocket the savings. In turn, providers and insurers who offered better value services would be rewarded with more business.

Those with low incomes or high health expenses would receive the assistance they need in buying necessary medical care and insurance through greater tax relief. At the same time, those who are healthier or more affluent would pay more in taxes, which would cover the cost of generous credits for the poor and the sick. But they would not object to this. They would quickly see the advantage of spending less of their income on unnecessarily generous health insurance coverage and instead taking the savings as (taxable) cash income to use for other purposes. The effect would be the same as paying more in taxes because you got a raise -- something few would find objectionable.

One of the important effects of this consumer choice system would be the creation of new incentives for preventive care, which would be of particular benefit to children. These incentives would take three forms.

First, consumers seeking the best value for their health care dollars will find that catastrophic insurance and preventive medical care give them the best return on their money. While a financially catastrophic medical condition could devastate an individual or family, premiums for catastrophic insurance are relatively cheap because such conditions are rare. Therefore, true catastrophic insurance offers the greatest ratio of protection to cost. Similarly, with relatively small investments in preventive care, individuals can avoid more serious conditions and larger medical bills, making preventive care a good value as well. Because under a consumer choice system, individuals and families pocket the savings, they will have an incentive to first pick catastrophic insurance and preventive care.

Second, basing tax relief on health expenses, both out-of-pocket and insurance premiums, means that individuals will receive the same help in buying preventive services as they do in buying insurance. Because the current system gives tax relief only for insurance, many people are discouraged from buying preventive services not covered by their insurance plan, which they must pay for out-of-pocket with after tax dollars.

Third, prohibiting health insurers from canceling policyholders means that insurers will be forced to manage long-term risks, like they do in life insurance, not short term risks, like they do in auto insurance. Investing in preventive care now pays dividends later in the form of reduced illness and costs. But in the current system, most health insurance policies are one year contracts. Thus, an insurer who offers preventive care benefits will face short term costs, but will probably not benefit from the future savings. However, when policyholders can renew coverage indefinitely, insurers will be forced to account for not only present but future costs as well. Thus insurers will quickly see that it is to their advantage to limit long-term potential liabilities by investing in preventive care.

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Neither a single-payer system nor a play-or-pay system would provide these incentives for preventive care. Both single-payer and play-or-pay systems are funded on an annual basis. The administrators of such systems, corporate or government officials, would not be as concerned with long-term costs as would insurers faced with the potential long-term liabilities associated with non-cancellable policies. Governments are notoriously short sighted, and in any employment based system employers can assume, given the increased mobility of the workforce, that at least a significant percentage of their employees will be working for someone else in future years.

Even more important, for preventive care to be effective it requires the willing and active cooperation and participation of the patient. But neither a single-payer system nor a play-or-pay system would provide patients with as strong a set of financial incentives to participate in preventive care regimes.

Another major advantage of a consumer choice system is that it would make health insurance portable, so that families wouldn't lose coverage when the breadwinner changed jobs. This would open up a new range of employment possibilities for all types of families. In particular, portable health insurance coverage would remove a significant barrier to more widespread self-employment. While a single payer system would offer the same portability of coverage, there would likely continue to be some problems in this regard under a play or pay system.

Families with more than one wage earner would also gain under a consumer choice health system. Currently, many of these families have double health insurance coverage. By converting to a single family policy they would be able to take home more in disposable cash income. Even in cases where one of the wage earners currently receives increased cash income in lieu of health benefits, the increased cash income does not usually equal the full amount that the employer would otherwise spend on health insurance.

Under a single payer system, a family with more than one wage earner would not be double covered, and so might also see some increase in cash wages. However, much of the potential increase would likely be taken in taxes to fund the system. The extent to which this would be the case would depend on the extent to which the system is financed out of payroll taxes. The burden of any payroll tax falls disproportionately on families whose income is primarily or exclusively from cash wages, as opposed to families who have significant non-wage income, or only one, well-paid wage earner with wage income above the maximum level of the payroll tax contribution.

How effectively double coverage would be adjusted for under a play or pay system is not clear. Again, there would probably still be some residual problems. If there is some exemption in a play or pay system for part-time workers, as is the case in most such proposals, it is quite likely that many secondary wage earners would see their employers reduce their hours to meet the exemption. The result, of course would be reduced incomes for those families.

Finally, in terms of the financial impact on low-income Americans a consumer choice system offers the most progressive financing mechanism of the three basic approaches. Under a consumer choice system, low-income individuals and families would pay less in taxes. Under either a single payer or a play or pay system, they would pay more in taxes since both systems would be financed out of regressive taxes.

To raise the enormous revenues required, any single payer system would need to be financed to a significant degree out of proportional or regressive taxes such as payroll taxes and sales or value added taxes. Indeed, this is how all national health insurance systems abroad are in large measure financed.

A play or pay system would be the most regressive of all. Whether employers complied with a coverage mandate by buying insurance privately for their low-income workers or paying a payroll contribution to a public program, the effect would be the same. Low-income workers would see their cash wages reduced. However, employers could not reduce cash wages below the minimum wage, so many of the currently uninsured would lose their jobs entirely.

In summation, I believe that a consumer choice health system, based on the kinds of reforms outlined above, holds the greatest promise for providing Americans with what they really want in health care -- a less costly, better value and more compassionate system that covers everyone.

Chairwoman SCHROEDER. Thank you very much.

And Dr. Johnson, thank you for being so patient. I know you too have to leave at 11:00. So let me get out of your way and turn it over to you. And the floor is yours.

STATEMENT OF ROBERT L. JOHNSON, M.D., F.A.A.P., DIRECTOR, DIVISION OF ADOLESCENT MEDICINE, UMDNJ-NEW JERSEY MEDICAL SCHOOL, NEWARK, NJ, AND CHAIR OF THE BOARD—THE CENTER FOR POPULATION OPTIONS, WASHINGTON, DC

Dr. JOHNSON. Well, Madam Chairwoman, either I will speak at lightning speed or I will catch a later plane.

I want to thank the committee for this opportunity to share my experiences with you on some of the issues which affect young people's access to health care in our country.

The adolescent is a poorly understood and perceived participant in the American health care system. Most of this misinterpretation is attributable to our failure collectively to understand the dynamic and psychosocial and growth processes which occur during the teenage years, and particularly to the relative absence, absence of the adolescent from the health care system.

There are very few specific adolescent diagnoses which we consider as serious. And this committee is an example today. Adolescents don't have most of these catastrophic illnesses. Therefore, we don't think of them as individuals who need a great deal of health care.

Let me quickly move on to some of the areas that I have experienced with my patients as barriers to health care. And the first is financial.

Of course, adolescents face the same financial access issues that plague all Americans. However, even if we have universal financial access to health care, adolescents will still face additional barriers.

For example, many plans require the beneficiary to identify themselves with a card or some other device which they present at the time they receive health care. This card is usually issued in the name of the primary beneficiary. And for most adolescents, that is a parent. Others may require signature of approval from that primary beneficiary.

Therefore, even in situations in which the adolescent is legally able to receive health care without parental knowledge, he is impeded from doing so. In my experience, this barrier has often led many teenagers to avoid care for many pressing issues.

In a similar fashion, we have problems with the prescription plan. One of my patients a couple of weeks ago came to our clinic because he had chlamydial infection. When I saw him a week later, he told me they hadn't gotten the prescription yet for doxycyclin because his mother had the prescription card and he didn't know how to steal it from her pocketbook.

Obviously, the adverse effects of this barrier would be mitigated if a card or identifier were issued in the name of all the members on the plan.

There are geographic barriers, as well. Limited health care manpower or the distribution of manpower affects the access of adolescents who live in parts of rural America where there are no or few providers of health care, or those who live in urban communities where the only providers of health care are in busy hospital emergency rooms.

These issues are very well known to the committee and I won't dwell on them, except to say that if we don't have immediacy of health care, especially for adolescents, then that health care is denied to them. And programs such as school-linked or school-based clinics and community centers have been effective in that area.

The third barrier is one of attitude. As I alluded to in the beginning of the statement, the adolescent has a vague identity as a health care consumer. He or she is infrequently seen consistently in most health care facilities and his or her identity to the system and the appreciation of his or her problems and the best way to approach them is usually based on biased stereotypes.

These stereotypes are usually limited in their recognition—limit the recognition of adolescence as a unique time period, and there is limited recognition of their unique psychosocial issues. And this often creates situations where the 12-year-old early adolescent is approached in the same manner as the 16-year-old middle adolescent.

Such approaches not only prevent effective communication between the adolescent and his or her health care provider, but they also impede effective health care as they may cause the health care provider to overlook many important health care issues.

For example, they may not question whether or not a 12-year-old is sexually active and not then test him for a sexually transmitted disease because there is a sense that 12-year-olds don't have sexually transmitted diseases. I must tell you that today, when I go back to Newark, I have a 12-year-old from suburban New Jersey who is coming to my clinic to receive his second injection for syphilis. And his pediatrician never thought that a 12-year-old might have sex. There are communication gaps.

The most consistent aspect of adolescence is the constant state of transformation that it is in. Not only does the individual adolescent experience rapid biological and psychosocial changes, the generation of adolescents also experiences an evolutionary metamorphosis.

Therefore, any service for adolescents must have the capacity to transform and modify itself in response to the transformations of the individual adolescent and the generation of adolescents over time.

For example, the programs that we started in the 70s—and I will tell you about one shortly—for disaffected adolescents who chose to leave home and run to the streets of our cities in protest of society must have evolved over the last 20 years to allow them to effectively respond to adolescents today who are on the streets because of poverty and homelessness.

To the extent that we fail to do this, we deny adolescents access to care with inflexible systems.

Fifth are the legal impediments. Currently, adolescents are allowed to consent to the diagnosis and treatment of sexually transmitted diseases, pregnancy related services, and substance abuse treatment in all states. In some states, health care enfranchisement extends to some psychiatric and emergency services.

The extensions of these rights was based upon the legislative concern that adolescents might delay or avoid treatment for some of these important morbidities because of the fear of parental retribution.

Beyond these specific statements in the law, there is a great deal of confusion about the ability of adolescents to consent to other forms of health care.

Some facilities require the parent to be present and actually in the examining room at all visits, creating obvious barriers to confidentiality, while others require parental signature on the first visit, and still others require that parents not be present at all.

Sixth are health care provider inadequacies. That is poor doctors. Many of the barriers which are created by health care providers could be mitigated if there was training in adolescent health care.

Currently, this expertise is largely limited to pediatrics, where training is mandated by the American Board of Pediatrics to include experiences in the care of adolescents and young adults.

Internists, family practitioners, general practitioners, obstetrician/gynecologists, emergency room physicians, all persons who care for a large number of adolescents, currently receive no specialized training in adolescent health care.

Seventh is the failure of comprehensiveness. The adolescent is a whole person who does not experience his or her problems in isolation from one another.

The young woman who needs help to pass an English class may also be depressed, sexually active in a nonprotective manner, experiencing major conflicts with her mother, and snorting P-dope between classes.

Therefore, any effective prevention or intervention must have the capacity to assess and analyze the entire universe of an individual adolescent's experiences, develop appropriate responses to these problems once they are identified, and fashion responses which are specific to the adolescent developmental stage but flexible enough to change as the adolescent grows and develops.

The failure of the health care system to respond with this level of comprehensiveness creates a barrier to the adolescent.

This issue is particularly significant as the adolescent may not be conversant enough to negotiate the complexities of the existing health care system and will tend to rely on one health care contact for the exploration of all his issues.

Therefore, the health care provider who addresses acne should have the capacity to determine the presence of and respond to issues relative to substance abuse, sexuality, sexually transmitted disease, and the consumption of excessive quantities of fat and sodium.

Now this form of health care can be provided comprehensively in a variety of settings that extend from private practice, school-based or school-linked systems, institutional settings, medical centers, and comprehensive community care centers. And all of these can provide excellent care.

I have been asked to describe one model of this system, and that is The Door.

This is a comprehensive community program with which I have been affiliated as a volunteer physician for 18 years, and where I am currently chairman of the medical board.

The Door began almost 20 years ago as our response to the needs of young people who were living on the streets of New York City.

The philosophy then and now is that a young person is best served if he or she can have all of his or her needs assessed and addressed in one setting, and if that setting coordinates its approach to these needs.

Today, The Door, which is now located in its own building in New York City's Lower East Side, has a collection of youth oriented services which include primary health care, family planning, nutrition, social service, mental health, substance abuse treatment and prevention, physical arts, basketball, weight-lifting, et cetera, creative arts, alternative education—there is a high school at the facility—vocational and educational rehabilitation, and legal services.

Young persons entering this facility today to join the gymnastics teams will also be assessed for their level of educational achievement, their need for educational assistance.

They will be evaluated to determine the presence or absence of patterns of substance abuse. They will be questioned to determine their need for counseling to assist them with inter and interpersonal relationship problems.

They will be assessed for their readiness for sports participation and given a comprehensive physical examination, which will also include an evaluation of their nutritional status, an evaluation of their risk for exposure to all sexually transmitted diseases, including HIV infection, a determination of their need for family planning services and exposure to a comprehensive collection of physical and emotional health preventive activities.

Every day the staff of approximately 70 individuals provide services for 250 to 300 adolescents from New York City, primarily from the five boroughs but also coming from New Jersey and Connecticut.

Finally, let me offer a few general recommendations for your consideration.

We must develop a health care consumer profile of the adolescent which will facilitate the institution of services which respond to their needs.

We must enhance the awareness and sensitivity of the health care provider system to the unique developmental and psychosocial issues of the adolescent.

This enlightenment should promote a greater receptivity to the adolescent as a patient and produce more effective responses to their problems.

We must develop a system which allows the adolescent full confidential financial access to care. This would include allowing adolescents to make independent financial consent for all health care services.

We must expand and clarify the adolescent's right to consent to health care services.

We must develop user friendly and flexible health delivery systems which are geographically accessible to adolescents.

And finally, we must design a health care system which is comprehensive enough to respond to all of the adolescent's needs or has the capacity for comprehensiveness.

Now with specific reference to comprehensive services, I have had the opportunity to review the draft of a bill which will soon be introduced by Senator Kennedy, the Comprehensive Services for Youth Act of 1992.

This piece of legislation contains most, if not all, of the points that I have made and I recommend this to the committee for your consideration and possibly support.

Thank you very much, Madam Chairman.

[Prepared statement of Robert L. Johnson, M.D., follows:]

PREPARED STATEMENT OF ROBERT L. JOHNSON, M.D., F.A.A.P., DIRECTOR, DIVISION OF ADOLESCENT MEDICINE, UMDNJ-NEW JERSEY MEDICAL SCHOOL, NEWARK, NJ, AND CHAIR OF THE BOARD—THE CENTER FOR POPULATION OPTIONS, WASHINGTON, DC

Madam Chairwoman, members of the committee, I am Dr. Robert L. Johnson, Director of the Division for Adolescent Medicine at the New Jersey Medical in Newark, N.J. and Chair of the Board of the Center for Population Options. As many of you know, the Center for Population Options is a Washington based national education and advocacy organization which strives to improve adolescent's transition to adulthood, with a comprehensive emphasis on all aspects health maintenance. Thank you for the opportunity to share my experience with you on the issues which affect the health care access of young people in our country.

The adolescent is a poorly understood and perceived participant in the American Health Care System. Much of this misperception is attributable to our failure to appreciate the nature of the dynamic pubertal and psychosocial maturation processes which occur during the teenage years and the relative absence of adolescent specific diagnoses from the list of the health problems which we as a nation have labeled as serious. As background to my comments, allow me to first discuss Adolescent Development and the aspects of this process which make our young people unique individuals within the health care environment.

PUBERTY

Puberty begins with an endocrinological cascade that starts in the brain in the area of the hypothalamus with the production of Releasing Hormones. These substances travel to the pituitary gland where they cause it to release another set of hormones known as Gonadotropins.

These substances stimulate the final stages of development of the testicles in the male and the ovaries in the female leading to the production of testosterone - the male sexual maturation hormone and estrogen and progesterone - the female sexual maturation hormones. These hormonal substances are largely responsible for the sexual development of the male and female adolescent.

FEMALE PUBERTAL DEVELOPMENT

The first visible signs of female puberty (average age range 9 - 13 years) are the appearance of breast buds under the nipples and the growth of pubic hair in the genital area. Her development over the next three years will include increased height and increased weight in addition to change in the size and contour of the breasts and increased amount and distribution of pubic hair. Puberty for the adolescent female ends two and one half years after the appearance of the breast bud with menarche (the first menstrual period).

This first menstrual period is a good historical marker for development in the adolescent female. Today most girls experience menarche somewhere between 11 and 11 1/2 years of age. Records from family bibles which recorded the age of attainment of womanhood (menarche) for girls living in the United States at the time of the American Revolution indicate an age of menarche of approximately 17 years. These same records indicate that at the time of the American Civil War the age of first menstrual period had dropped to 15 1/2 years. At the beginning of this century the average age of menarche had decreased to 13 years. As I indicated above, currently the average age of first menstrual period is 11 1/2 years. Indeed the age of menarche has been decreasing by approximately 2 to 3 months for every decade since the beginning of this century.

This biological observation has profound social implications. Pregnancy at ages as early as 11 are partly more common today than they were in the 1950's because of the

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acceleration of the age of biological maturity. In the 50's, there were very few 11 year old young adolescent females who could become pregnant! Furthermore, this commentary is irrefutable evidence that our children are growing up faster. The 13 or 16 year old of the 1990's is indeed different from the 13 or 16 year old of the 1950's.

One of the more difficult problems that we adults have in our relationships with adolescents is our tendency to conceptualize "teenage normality" in the context of our own adolescence rather than the context of contemporary adolescents. Our context however may be 10, 20, 30 or 40 years out of synch with the adolescent of the 1990's and therefore superfluous. We must be certain that our concepts of the current adolescent, whether they be biological or psychosocial concepts, are contemporary and relate to the adolescent as he/she is today, not as he/she was yesterday.

MALE PUBERTAL DEVELOPMENT

Puberty in the adolescent male (average age range 11 - 18 years) begins with the enlargement of the testicles. This event which is attributable to the opening of the tubules inside the testicle as they increase production of spermatozoa, is followed by growth of pubic hair and increase in the size of the penis. Throughout the developmental process the young man's total body size increases as the result of rapid growth in both height and weight.

Male adolescent maturation occurs over a six year period of time as compared to three years in the adolescent female. In addition, the typical male will initiate pubertal events one and one-half years after the typical female.

There is no event in the male adolescent which is exactly comparable to menarche - the first menstrual period. It has been suggested however that the first "wet dream" indicates a time at which the male is producing sperm at a rate and amount great enough to significantly increase the probability that ejaculation during sexual intercourse will cause pregnancy. This event has been called semenarche and it normally occurs at age 13 +/-1 year.

ADOLESCENCE

Adolescence is a period of time that we have set aside in our culture for our children to learn how to be adults. In an earlier time in history our children were directly taught the Lesson of Adulthood. For example, consider the adolescence of the young Kunta Kinte which was eloquently described by the late Alex Hailey in his book **Roots:**

> "at about 12 years of age the boys of the village were separated from their families and taken to a camp in the jungle by the men of the community. Over a period of 6 weeks, the boys were taught all of the lessons of adulthood. At the end of the encampment they were tested to determine if they had learned these lessons of adulthood. Those boys who successfully passed the test were granted adult status and they were circumcised as a visible sign of their manhood. They left their village as boys and they returned to the village and to their society as men."

THE TASK OF ADOLESCENCE

Young men and women growing up in our culture must accomplish the same Task of Adolescence as Kunte Kinte - they must:

1. **Emancipate** themselves within the structure that gave them nurture and support during their childhood (usually the family or some similar surrogate structure);
2. establish their **Sexual Identity** - make decisions about maleness and femaleness and love-object gender, pa

3. establish their **Intellectual Identity;**
4. establish their **Functional Identity** and decide "what they are going to do with the rest of their lives" - how they will support themselves and contribute to their families and to society;
5. complete **Cognitive Development.**

In our modern culture their are no short concentrated periods of instruction in manhood or womanhood. Their are no test which prove that boys and girls in our culture have become men and women. There are no societally recognized ceremonies which mark the transition from childhood into adulthood and there are no visible signs of that new status.

The adolescence of the American teenager is drawn out over a protracted period of as many as 10 to 15 years. They learn how to be men and women not from lessons which are carefully taught by the adults of our society but from observations that they make of important adults in their lives. Often these important adult role models are found in the family; but if the quality and quantity of this observational contact is impaired, limited or absent, this component of the lessons of manhood or womanhood may be abdicated to the streets or to the media. School has become another important source of instruction in adulthood in our culture. School is the first environment outside of the home within which the lessons learned at home can be tested. Furthermore, the quality of educational exposure will be a major determinant of the scope of possible Functional Identities.

Finally, in America our children learn important lessons about adulthood from the media. The media has effectively established standards and norms of behavior which have crossed color, economic and educational lines. Eight ball jackets, for example, are currently a symbol of adolescent status that applies equally to adolescents in every ethnic, racial and economic group. Indeed they have become so important that our children are "killing each other to get them." Much of the appeal of this and other contrived symbols is attributable to their association with desirable media images.

However, before we lay an excessive blame on the media let me reiterate that the effect of the media on an individual adolescent will be a function of the quality and the quantity of the lessons presented within the family context.

THE STAGES OF ADOLESCENCE

Adolescence is divided into three stages, early adolescent, middle adolescence and late adolescence.

EARLY ADOLESCENCE

The early adolescent (typical age range 12 - 14 years: see Table 1) is caught in the midst of rapid body changes - secondary sexual characteristics begin to appear, growth accelerates and biology becomes a major focus of daily concerns. Cognitively, these young people possess thought patterns which are still relatively concrete; they have difficulty projecting themselves into the future. This becomes a particular problem in many health care settings when they are asked to modify their behaviors and delay gratification for some distant future goal.

Although the early adolescent may test adult authority within the family "to see what they can get away with," they will generally acquiesce to parental guidance. In this stage they also begin to identify their peer group in an effort to find other young people who they sense are similar to themselves.

In the area of sexuality, there is commonly testing of some sexual behaviors but sexual activity is usually limited. Many adolescent males who will become sexually active during adolescence will typically initiate sexual intercourse during this stage (age 13 - 14). However, they don't usually become regularly sexually active until they approach biological maturity (16- 17 years). Nevertheless, health contacts during this stage should consider all of the possible diagnoses related to sexual activity.

MIDDLE ADOLESCENCE

Middle adolescence (typical age range 15 - 17 years: see table 2) is the developmental home of the majority of the problem behaviors found in all adolescent population groups. The transitions in this stage are so dramatic that they seem to occur overnight. The secondary sexual characteristics become fully established and the growth rate decelerates. Physically they now look more like the adults they will become and less like the children they were.

The psychosocial hallmarks of this stage are the development of abstract thought patterns and the attainment of a set of psychological supports that I have called the Armor of Middle Adolescence. This important protective gear consist of the **Helmet of Omniscience** which makes them all knowing, the **Breast Plate of Omnipotence** which makes them all powerful and the **Shield of Invincibility** which gives them the ability to defend against and defeat every foe.

This Armor of Middle Adolescence is a duel functioning double edged sword. The Armor provides the supportive structure which allows these young people to emancipate themselves and move outside of the structure which had nurtured and sustained them for most of their lives. But, it also allows them to participate in dangerous and destructive Risk Taking Behaviors, believing that they can not be harmed. For example "I can pass a test without studying," "I can drive a car even though I have never taken a driving lesson," " I can steal a car and not get caught," " I can stop a bullet and not die," "I can have unprotected sexual intercourse and not get pregnant."

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In this stage most adolescents began the process of Emancipation from the limitations of the structures which supported their childhood. In many families the struggle for Emancipation is played out through major conflicts over parental control and authority. Often the battles move outside of the home environment to encompass a challenging of authorities in other arenas - e.g. school, police, health care providers.

As adolescents separate from their families they cleave more tightly to the peer group that they defined for themselves in early adolescence. Within this context the peer group begins to define the rules of behavior. Additionally, the peer group acts to affirms and reaffirms the adolescent's self-image.

The peer group is often cited as the source of many problem behaviors because of the pressure it brings to the adolescent to conform to its norms and codes of behavior. However, since these young persons define their own peer group according to their self identity, and since they participate in the definition of the peer norms and behavioral codes they thus share responsibility for their own actions within the group as well as outside of the group.

Sex and sexual expression is a major focus of the lives of middle adolescents. Adolescent females who will become sexually active during adolescence will typically have their first sexual experience during this stage. Both the young men and the young women suddenly seem to become sexual in all aspects of their being. The health and social risk associated with unprotected sexual intercourse become issues of paramount importance during this stage. These destructive effects however are somewhat ameliorated if the adolescent has been adequately exposed to protective practices prior to middle adolescence.

LATE ADOLESCENCE

The late adolescence (typical age range 18 + years: see table 3) has attained full physical maturity. Cognitively they achieve formal operations and they become fully aware of their limitations and how their past will affect their future. Within the family they move to a more adult to adult relationship their parents. The peer group recedes in importance as a determinant of behavior; and sexuality becomes closely tied to commitment and planning for the future.

The foregoing has been a description of the dynamic context within which all adolescents experience their lives. Within that context most American adolescents pass from childhood into adulthood with few problems. Some of these young people however become involved with one of a variety of encumbrances - drugs, alcohol, premature parenthood, violence, suicide, school failure/dropout, delinquency, et cetera ad infinitum - which impedes their orderly transition. All of these problem behaviors of adolescence are related to and are affected by the developmental and maturational scheme that I have outlined above. Additionally, as these behaviors have common origins they also tend to occur in some combination within the same individual.

HEALTH CARE BARRIERS

Now that I have described the biological and psychosocial context of the American Adolescent let us look at the barriers they face within the health care system:

1. **Financial Access**

   Of course the adolescent faces the same financial access issues which plague all Americans. However even if there is universal financial .pahealth care enfranchisement there are additional issues which complicate confidential health care access for adolescents:

- many plans require that the beneficiaries identify themselves with a card or some other device which may be issued only in the name of the primary beneficiary (a parent). Others may require the signature or approval of the primary beneficiary. Therefore, even in situations in which the adolescent is legally able to receive care without parental knowledge he/she is impeded from doing so. In my experience, this barrier has often led many adolescents to avoid bringing pressing issues to medical attention.
- a similar problem occurs with prescriptions plans as the recipient of the prescription is usually required to present a card prior to he filling of the prescription. I have had several patients in my practice who did not receive treatment for sexually transmitted diseases because they couldn't get the prescription card from their mother.

Obviously the adverse effects of this barrier would be mitigated if a card or other identifier were issued to each family member.

2. Geographic Barriers

Limited health care manpower or the distribution of that manpower affects the access of adolescents who lives in parts of rural America where there are no or few providers of health care or, those who live in urban communities where the only providers of care in a hospital emergency room. The issues relative to the inefficiencies of this aspect of our health care system are well known to the members of this committee. Health care which requires the expenditure of extended

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amounts of time either traveling great distances or waiting for hours in busy emergency rooms is often health care denied.

- As we embrace the wisdom of systems which are designed to provide preventive as well as comprehensive care for the adolescent we are also faced with the need for these services to have immediacy. The adolescent will most beneficially utilize health services which are most convenient - that is located within his immediate environment, i.e. based in or linked to a school or community center.

3. **Attitudinal Barriers**

As I alluded to in the beginning of this statement the adolescent has a vague identity as a health care consumer. Since she/he is infrequently seen in most health care facilities, his/her identity to the system and the appreciation for her/his problems and the best way to approach him/her are usually based on biased stereotypes. These stereotypes are usually limited in their recognition of any of the adolescent's unique developmental and psychosocial issues - often creating a systems which responds to the 12 year old early adolescent with the same approach used for the 16 year old middle adolescent. Such approaches not only prevent effective communication between the adolescent and their health care provider they also impede effective health care in that it causes the health care provider to overlook important health issues. Questioning about sexual activity may be overlooked because "these kids are just too young to have sex" or every inner city teenage girl with abdominal pain may be assumed to have had salpinigtis "because those kids have sex all the time."

4. Communication Gaps

The most consistent aspect of Adolescence is its constant state of transformation. Not only does the individual adolescent experience rapid biological and psychosocial change, the generation of adolescence also experiences its own evolutionary metamorphosis. Therefore any service for adolescents must have the capacity to transform and modify itself in response to the transformations of the individual adolescent and the generation of adolescents. For example, the programs we started in the 1970's for disaffected adolescents who chose to leave home and run to the streets of our cities in protest to society must have evolved over the last 20 years to allow them to effectively respond to adolescents who are on the streets today because they have been forced there by poverty and homelessness. To the extent that we fail to respond to the changes that occur in adolescent populations and develop and rely upon inflexible systems we create a barrier which prevents us from becoming effective health care providers and prevents the adolescent from becoming an effective health care consumer.

5. Legal Impediments

Currently, adolescents are allowed to consent to the diagnosis and treatment of sexually transmitted diseases, pregnancy related care, and substance abuse treatment in all states. In some states this health emancipation extends to some psychiatric and emergency services. The extension of these rights was based upon the legislative concern that adolescents might delay or avoid treatment for these important morbidities because of the fear of parental retribution.

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- Beyond these specific statements in the law there is a great deal of confusion about the ability of adolescents to consent to other forms of health care. Some facilities require the parent to be present and actually in the examination room at all visits creating obvious barriers to confidentiality, others require a parent's signature at the first visit, still others have no requirement that the parent be present.

  In reality I find that most parents who are appropriately involved with the health of their children recognize the wisdom of the health emancipation of their teenagers. Although they rarely accompany their children to my office after the first visit they maintain communication with me by telephone and they are happy that they are not required to lose time from work to attend our clinics.

- One additional issue relates to the adolescent proclivity to have a hidden agenda as the reasons for health visits. For example, during a routine physical examination an adolescent female may want to have or need to have a test for STD's. If her mother is in the room the health care provider may not ask if she is sexually active, or if she/he does ask the adolescent patient may feel compelled to give a false answer.

6. **Health Care Provider Inadequacies**

Many of the barriers would be breached by health care providers who had training in adolescent health care. Currently this expertise is largely limited to Pediatrics where training is mandated by the American Board of Pediatrics to include experience in the care of adolescents and young adults. Internist, Family Practitioners, General Practitioners, Obstetrician Gynecologist, Emergency Physicians who care for a large number of adolescents currently received no specialized training in Adolescence Medicine.

7. **Failure of Comprehensiveness**

The adolescent is a whole person who does not experience his/her problems in isolation from each other - the young woman who needs help to pass her English class may also be depressed, sexually active in a non-protective manner, experiencing major conflicts with her mother, and snorting P-dope between classes. Therefore, any effective prevention or intervention must have the capacity to:

a. access and analyze the entire universe of an individual adolescent's life experiences;

b. develop appropriate responses when problems are identified; and

c. fashion responses which are specific to the adolescent developmental stage but flexible enough to change as the adolescent develops.

- The failure of health systems to provide this level of comprehensiveness creates a barrier to the adolescent. This issue is particularly significant as the adolescent may not be conversant enough to negotiate the complexities of the existing health care system and will tend to rely on one health care contact for the exploration of all of his problems. Therefore the health care provider who addresses acne should have the capacity to determine the presence of and respond to issues relative to substance abuse, sexuality and sexual activity as well as the consumption of excess quantities of sodium and fat.

HEALTH CARE SETTINGS

Health care for adolescents can be provided adequately in a variety of settings:

1. Private Practice Model (individual and group practice as well as managed care systems)
2. School Based/School Linked Systems
3. Institutional Settings (Job Corps, Military, Prisons)
4. Medical Centers
5. Comprehensive Community Programs

All of these settings have the capacity to adequately respond to the health needs of the adolescents and, given financial and legal access, to provide excellent care.

I have been asked to describe a model of one of these systems - The Door, a comprehensive community program with which I have been affiliated as a volunteer physician for 18 years and where I am currently the Chairman of the Medical Board. The Door began almost twenty years ago as our response to the needs of young people who were living on the streets of New York City. The philosophy then and now is that a young person is best served if he/she can have all of his /her needs accessed and addressed in one setting; and that setting should coordinate its approach to those needs. Today the Door, which is now located in its own building on New York's lower west side has a collection of youth oriented services which include primary health care, family planning, nutrition, social service, mental health, substance abuse treatment and prevention, physical arts (basketball, weight lifting, gymnastics, volley ball, dance), creative arts, alternative education (The Umoja Alternative High School), vocational and education rehabilitation, and legal services.

Young persons entering the facility today to join the gymnastics team will also be assessed for their level of educational achievement and the need for education assistance; evaluated to determine of the presence or absence of patterns of substance use or abuse, questioned to determine the need for counseling to assist with inter- as well as intrapersonal relationships; assessed for their readiness for sports participation; and given a comprehensive physical examination which will also include an evaluation of their nutritional status, an evaluation of their risk of exposure to all STD's including HIV, a determination of their need for Family Planning services and exposed to a comprehensive collection of physical and emotional health preventive activities. Every day the 70 staff members provide these services to 250 adolescents who are primarily from the five boroughs of New York but also come to us from New Jersey and Connecticut.

RECOMMENDATIONS

Finally allow me to offer a few general recommendations for your consideration:

1) We must develop a health consumer profile of the adolescent which will facilitate the institution of services which will respond to their needs.
2) We must enhance the awareness and sensitivity of the health care provider system to the unique developmental and psychosocial issues of the adolescent. This enlightenment should promote a greater receptivity to the adolescent as patients and produce more effective responses to their problems.
3) We must develop a system which allows the adolescent full confidential financial access to care. This would include allowing the adolescent to make independent financial consent for all health services.

4) We must expand and clarify the adolescent's right to consent to health care services.

5) We must develop user friendly and flexible health delivery systems which are geographical accessible to all adolescents.

6) Finally, we must design health care systems which are comprehensive or have the capacity for comprehensiveness.

TABLE 1

CHARACTERISTICS OF EARLY ADOLESCENCE

GROWTH	1. Secondary sexual characteristics appear
	2. Growth rapidly accelerates
COGNITION	1. Concrete thought patterns
	2. Limited perception of long-range implications of current acts and decisions
SELF IMAGE	1. Preoccupation with rapid body changes
	2. Disruption of former body image
FAMILY	1. Testing of boundaries of independence
	2. Few major conflicts over parental control
PEER GROUP	1. Seeks peer affiliation to counter generative instability
	2. Identification of peer group based of similarities of interest and behaviors
SEXUALITY	1. Self exploration and evaluation
	2. Limited intimacy

TABLE 2

CHARACTERISTICS OF MIDDLE ADOLESCENCE

GROWTH	1. Secondary sexual characteristics well established 2. Growth decelerates
COGNITION	1. Rapidly gains competence in abstract thought 2. Variably applied appreciation for the effect of current acts and decisions on the future 3. The Armor of Middle Adolescence
SELF IMAGE	1. Reestablishment of body image 2. Preoccupation with fantasy and idealism
FAMILY	1. Major conflicts over control 2. Struggle for emancipation
PEER GROUP	1. Strong need for identification to affirm self image 2. Defines codes of behavior
SEXUALITY	1. Multiple plural relationships 2. Heightened sexual activity 3. Establishment of sexual idenity

TABLE 3

CHARACTERISTICS OF LATE ADOLESCENCE

GROWTH	Final stages of physical maturation process
COGNITION	1. Formal operations established 2. Intellectual and Functional Identities established
SELF IMAGE	Life-goal indecisions may develop as limitations on expectations are realized
FAMILY	Transposition from child-parent dependency relationships to adult child-adult parent model
PEER GROUP	Recedes in importance as major behavioral determinant
SEXUALITY	1. Movement to stable relationships 2. Expanded capacity for mutuality and reciprocity in relationships 3. Intimacy tends to involve committment rather than exploration and romanticism

Chairwoman **Schroeder**. Thank you very much, Dr. Johnson. And I must say that is the most comprehensive overview of adolescent problems I think I have ever heard. I mean, your sensitivity shows tremendously. Thank you very much for helping us.

I want to thank all the panel. And I know we promised some of you could go at 11:00. And if you need to go, please do, because we didn't mean to hold you hostage here by any way, shape or form. We really do appreciate the very thorough testimony you have.

Congressman Wolf, do you have any questions of anyone who can remain?

Mr. **Wolf**. I do. Mr. Haislmaier, if you are going to leave, maybe you could just answer the first question.

Mr. **Haislmaier**. Sure.

Mr. **Wolf**. But if you have to leave, I don't want to keep you.

Mr. **Haislmaier**. I just have an 11:30 flight. That is all. I have to go speak to insurers in Ohio and tell them how to fix their industry.

Mr. **Wolf**. Well, why don't you go. Go ahead.

Mr. **Haislmaier**. No, that is all right.

Mr. **Wolf**. What country do you think is doing the best job in this area?

Mr. **Haislmaier**. I don't think any particular country with a national system is doing an outstanding job. What is interesting is that I think we can learn from bits and pieces in different places.

For example, the British private system is a fascinating study. The British have a comprehensive national health system, but they also have a private system. Indeed 12 percent of the population now has private health insurance, and even more don't even buy the insurance. They just buy private operations directly when they need them.

It is amazing what you find in that kind of a market, because it has largely been left alone by the government. There are no distorting tax or regulatory policies. The only regulations are basic insurer solvency laws and requirements that the providers be certified and competent.

You can get price lists in a British private hospital. They will just give you a list of the prices. They will even guarantee the prices. They will say, for example, this is what a hip replacement cost. Indeed, over Christmas some hospitals ran sales, offering 20 percent off their normal prices. I have clippings from the London Daily Telegraph clippings reporting on this.

Now such behavior makes perfect economic sense, because most people don't like to be in a hospital over Christmas. But the hospital has a lot of fixed costs. So they ran sales.

When I talked with executives of British private health insurance companies, I asked, "Would you cancel people or triple their premiums because they had a big operation last year?" They said, "My God, no, we wouldn't do that! If we did that no one would buy our insurance because it would be a bad value, and wouldn't give them the long-term protection they want."

So the point I would simply make is if you look at some bits and pieces of other systems—and I am looking at a similar situation in New Zealand now, though I haven't looked at it in much detail yet—there are some examples of things that maybe we can learn from.

As another example, the Australians have a private, individual system but it is very heavily regulated and it does have some problems.

Mr. Wolf. Thank you very much.

Ms. Brown or Dr. Nelson, what country do you think is doing the best job? And I will add one question and maybe one of you can take one and one of you can take the other.

You know, you make a compelling case. How do you pay for it? What is your means of payment for what you recommend?

Perhaps, Doctor, you might cover the first question. What country do you think is doing the best job? And then Ms. Brown could cover the question of payment.

Dr. Nelson. The Western European democracies are spending, as you know, between six and eight or eight and a half percent of their gross national products on health care, in contrast to our 11, 12 percent.

Most people that have studied the availability of care in those systems realize that it is at least as good, if not better, despite some waiting lists for elective procedures.

The conviction we have is that what characterizes most of those systems is that they put a lot of resources up front in preventive care, supporting young parents through home visiting, through providing immunizations and other sorts of care, and in trying to minimize the beginnings of chronic disease that are so costly.

Mr. Wolf. Does that deal with smoking and drinking and drug abuse?

Dr. Nelson. Yes. Now that doesn't mean those countries don't have those problems. They do. But one of the explanations for why the relative percent of their GNP is much lower than ours is that there is an emphasis on prevention and those services are universally available.

Mr. Wolf. But do you have one or two countries that you think far exceed the others that we could look into, that you think are doing a better job, perhaps one in prevention and another in treatment?

Dr. Nelson. Well, each of these countries is different. The Scandinavian countries have very strong prevention programs. And Germany, despite all the problems that are occurring apparently this week there, has a nationally regulated insurance industry that seems to provide better universal access than our system.

I think we ought to look at those countries that have greater similarity to us, rather than difference, because it is very hard to transpose.

Most of the attention, of course, has been focused on the Canadian system in comparison.

Mr. Wolf. Yes. I get that a lot.

Dr. Nelson. And while I don't have the personal knowledge about the Canadian System, it is clear that the Canadian system has allocated health care dollars in a somewhat different way. And again, preventive services and catastrophic services are available to the population. Yes, some people choose to purchase additional services outside the system, even coming into the United States to obtain care. But basic services are available.

Mr. Wolf. Ms. Brown, would you care to go over the cost, what do you recommend?

Ms. Brown. Many of the issues most central to maternal and child health offer, in fact, substantial promise of cost savings. For example, some of the health services most important to this population are preventive services, which have been shown to be cost effective, that is cost saving.

The ones I mentioned, for example, were prenatal care and immunizations, family planning. I think it is an open and shut case that we save money by making those services widely available.

Another source of cost savings in health care reform is decreasing the chaos, paperwork and complexity in the health care system that is costing us all enormous amounts of money. To the extent that the Congress can find ways to simplify the overall system, we are going to realize enormous cost savings, as suggested by the GAO just recently.

Just as a personal comment: I am the health care manager in our little family, and the amount of time I spend on claims, contesting denied claims, and on Xeroxing and mailing health insurance claims forms, etc. is extraordinary. If you multiply these efforts across the whole population—in doctors' offices, in hospitals and clinics—it is clear that a "simplification agenda" is what's needed.

Mr. Wolf. Do you think it would make the difference?

Ms. Brown. I think it would make an enormous difference. Many of the current crop of health care reform bills, incidentally, do talk about simple things like universal claim forms and increased electronic billing. I think everybody is beginning to understand that we are wasting enormous amounts of money—not on treatment or care or prevention—but on paperwork.

Another aspect of the cost issue to consider is that many current expenditures are flowing through the system in relatively "hidden" ways—expenditures that could be harnessed more effectively.

I mentioned, for example, uncompensated care, and the need to find a financing source for people who contribute to that pool—the uninsured. Expenditures for the uninsured are already flowing through the system. They are displayed, however, on a different ledger than the health insurance ledger. Their care appears on the hospital uncompensated care ledger, which in turn is met then by private contributions, higher insurance premiums for those who are insured, and so forth.

In short, I don't think it is prudent to approach the issue of health care reforms with an overwhelming concern about where and how to finance the improvements. The monies are already being spent, but they are often being spent in a chaotic and an ineffective way.

Mr. Wolf. You are saying we could better spend the money that we are spending and deal with most of the problem?

Ms. Brown. Well said.

Mr. Wolf. Well, I appreciate it. It is very important. And I have a number of family and friends who have children who have juvenile diabetes and it is very difficult for them. It is a real problem.

Every time we look at initiatives, we should also look at how we are going to pay for them. But I think you make a very good case.

Dr. Johnson, let me ask you a question. And I don't mean this too much in a sense of criticism. But the one thing that came through to me with your testimony is you pretty much zeroed out the parent. I mean, you never mentioned mom or dad in your testimony at all.

Do you think there is any involvement? Or where are you on this question with regard to parental involvement?

Dr. **Johnson**. Well, Mr. Wolf, when you read the entire testimony, there is a large section on the adolescent's relationship with his or her parent. And of course, the parent is the most important individual in the adolescent's life.

One of the things that we try to do, however, is to turn the adolescent into the person who is responsible for their own health care. And as a young person enters the teenage years and as they move through on into adulthood, we look at them taking increasing amounts of responsibility to make sure that they do whatever must be done in order to assure their continuing health care, and that they become good health care consumers.

For example, when a young person comes to my practice or to the clinic, usually at 12 years of age they come on their first visit with the parent. And a good 25 percent of that visit is spent with the parent, but I usually see the adolescent alone.

Part of that visit is educating the parent to the expectations we have for this 12-year-old. The 12-year-old will give their own history and know their own history. The 12-year-old will be responsible for making sure that they take their own medications. And there is a large degree of parental involvement at the beginning of that process. As the young person becomes older and older, they take on more and more responsibility.

One of the effects of this is that when the teenager reaches a point where there is conflict between the parent and the child, health care does not become one of the issues that is used in that conflict.

So the parent is extremely important. And with the psychosocial issues there is another dimension of parental involvement.

In the need to condense these statements, I took out most of those references.

Mr. **Wolf**. Thank you very much. I appreciate that.

Chairwoman **Schroeder**. Thank you. Congressman Barrett.

Mr. **Barrett**. Thank you, Madam Chair.

Ms. Brown, you talked about several of your goals. And I think in number three you talked about the medically underserved. And I guess because I come from a largely rural district, I am wondering if perhaps you could embellish a little on your resource development, I believe is what you talked about in number three.

Ms. **Brown**. Although many of the reform bills focus heavily on financing health care, they often ignore the important area of resource development. In stressing "resource development," I am suggesting that providing access to insurance will not solve access problems in rural communities or in some innercity communities.

Clearly, we do not have enough qualified doctors, nurses and clinics in some of the most medicially under served areas. And the idea that an insurance card is going to somehow magically fix that has, I think, been proven wrong time and time again. Clearly, we need to focus on getting actual people, doctors, nurses and so forth, and services, actual clinics and places people can go, into underserved areas.

Having said that, there are many ways to proceed. There is no one way to get people and services into a community. There are a whole range of grant programs that have been very successful. There are these tuition and loan repayment programs, such as the National Health Service Corps. And there are other social experiments that have been tried in this area of resource development. We need to review those, to build on the best of them, and link the best of them to changes in financing.

Mr. BARRETT. With emphasis entirely on accessibility?

Ms. BROWN. The point is that if there is no place to go, no provider to see, having an insurance card isn't going to help you. For example, many places in the country have clinics serving largely a Medicaid clientele that have three, four, five week waiting lists for prenatal patients. These patients have a payment source for care, but there are no charge doctors and clinics who will care for them in a timely manner.

The point is that we must offer both a financing source and somebody to go to with your insurance card. And as I said, there are many ways to do that. There is no single approach in this country to really do much of anything, I think.

Mr. BARRETT. I guess finally, you then took us into some solutions about provider distribution. And you talked about the direct placement of health care providers in medically underserved areas by the National Health Service Corps.

And I guess my question is essentially, give me just an off the top of your head opinion of the National Health Service Corps?

Ms. BROWN. Well, I am one of its greatest fans.

Mr. BARRETT. Are you?

Ms. BROWN. Yes. Because I have had a lot of experience on a personal level with Health Service Corps providers. We can no longer assume that market forces alone are going to take people to Zuni, New Mexico or the District of Columbia, for that matter. The National Health Service Corps has the capacity to place providers in communities that do not naturally attract them, for whatever reason, poverty, geography, whatever. The Corps is able to put providers in community health centers, in a wide variety of clinics and elsewhere so that there is a doctor, a nurse or other trained care giver available to take care of people even in medically underserved areas.

The Corps has been a very, very successful mechanism using school tuition in exchange for service. I think it offers a "win/win" formula that has helped us in this provider distribution problem.

Mr. BARRETT. That program is successful? It is adequate in your opinion, I take it?

Ms. BROWN. Well, I don't think we have a large enough Corps at present. But I think that the model has been proven time and again to work. Remember that when the National Health Service Corps was almost dismantled in the mid 80s, a number of states tried to develop their own state analogs to the Corps because they had come to depend on the providers it supplied for some of the states' neediest areas.

So the proof is in the pudding. The states tried to recreate the Corps and fill the gap when it was almost eliminated; though recently there has been some resuscitation.

Mr. BARRETT. Thank you. Thank you, Madam Chair.

Chairwoman SCHROEDER. Thank you. Congressman Holloway.

Mr. HOLLOWAY. Thank you. First of all, Ms. Brown and Mr. Wolf touched on this. But in your study, you quoted from it to say that actually no formal cost analysis was attempted. And of course, we are always looking at the surveys. But the surveys show that a minority of the people in this country, when surveyed, are even willing to spend $25 a year additional for health care or to provide social programs of health care.

Where do we get the money from? I mean, we talked about in one of the studies—Congressman Russo, he has a plan but he has been defeated. So his plan wasn't too big in his district.

Ms. BROWN. I know.

Mr. HOLLOWAY. So I think we all, as members knowing the position of America—and I guess the question I would like you to answer at the same time is, the panel we had earlier before you, Ms. Renshaw and Ms. Weaver, definitely are middle class Americans, what I would consider, and of course I grew up in a very low middle class, if you call it. Back then we didn't know what classes there were.

But who really is hurting for health care more today? I think the poor have so many government programs they can lean to, no matter what the illness. And yet middle class America a lot of times—how do we address—I guess I am looking for an answer, but the number one question is, how do we pay for it? And then why don't we always include this in suggestion to us? If you are going to tell us what we need, tell us how we are going to pay for it.

Ms. BROWN. First, I want to clarify this comment about no formal cost analysis was attempted. The Institute of Medicine report that I have been referring to did not outline a bill or formal proposal for reform. To make cost estimates, you must have a definite plan to run through a Univac cost-estimating brain. But because we offered no single plan of our own we made no formal cost estimates.

We did, however, look at the cost estimates associated with the seven bills that we examined.

I already responded to Mr. Wolf about some of the sources of revenue for health care reform. But, fundamentally, meeting the cost challenge centers on choices and on political will.

The Congress and the American people have repeatedly expressed willingness to pay for certain major undertakings, the savings and loan bailout being one of the more recent along with the Persian Gulf war. We are able to come up with large sums of money when we feel the need is great.

The issue is, are we willing to put health care reform in the category of an effort where we might—I underline might—need to spend some additional revenues. My clear belief is that we should.

Worry about the health care system, as you yourself mentioned, has now spread throughout the country. We, have, for example, relatively wealthy people unable to get health insurance due to preexisting condition exclusions. And although the consequences for these individuals clearly are not as great as for low income people, the point is that problems of uneven and insufficient insurance coverage are now national problems. They are no longer confined to any particular group or geographic area.

So I think the question is whether or not the Congress is going to recognize the depth of this problem and the distress in the land, and then be courageous enough to put some new revenues towards a solution, although, as I said, I think that is really not the issue here, given the amount of waste that we have and duplication and paperwork, given the amount that we fail to spend on preventive services that are cost effective, and the other points I made to Mr. Wolf as well.

Mr. HOLLOWAY. Well, if I can interrupt you there, we have often tried to attempt the waste, new items, any way you can go at it. I don't think government has proven that we are not efficient at doing anything. If it is something that we are not efficient at, I wish you would bring it out to me, because I would like to go out and ring our bell somewhere.

But I don't see us getting any more efficient. I would agree that Ms. Brown probably had some great suggestions and paperwork definitely is the number one. But we are not the best people to do that. I mean, where do we come from? Who can address it better than government? Because we are not the one to do it. Or if you do, you are going to have to start showing me some places we are good at doing it.

Ms. BROWN. Mr. Holloway, many of the current proposals on the table are so-called multi-payer plans that retain the current mix of public and private insurance. They propose that we continue to rely on hundreds of private insurance plans, the Medicaid program for very low income people, (which of course itself is more than 50 individual state-run programs), and then a wide variety of publicly financed programs and risk pools in the middle, various publicly financed programs.

The inherent complexity of these programs, produces a level of chaos that is really quite incomprehensible. I often wonder how people are supposed to move among all these plans. They are insured under their business for a while, so they have private insurance. Then they are out of a job, so they go into a newly created public program. Then maybe they fall below the poverty line, they are on Medicaid, back and forth, and back and forth. Surely the government can improve on this degree of complexity! It is the current complexity, in part, that leads to all this chaos and churning and expense.

Mr. HOLLOWAY. Go ahead, Doctor.

Dr. NELSON. Could I also respond, Mr. Holloway? I know, by virtue of the fact that you are a part of this select committee, you are especially interested in children and families. But I think one of the things we feel very strongly about—and it may seem trite but it is not trite when you move out into the world—is that with this issue, with health care reform, I think children and young families do get lost in the discussion, despite the fact that they are really, as a population, the most vulnerable right now.

When you look at uninsured or underinsured Americans, and whether you talk about 37 million at one point in time or 50 million over the course of a 12 month period, that number includes a disproportionately large population of children and young adults who are in the kinds of jobs that don't provide benefits.

And I am afraid that as those in my generation approach retirement and want to make certain that Medicare and the private supplementation meet our needs, we are going to forget about these young families and children, whose situation is really deteriorating in our country now because of the kinds of jobs that are available for a lot of young people.

I agree with Sarah, there is a tremendous amount of duplication and needless complexity in the system. I think just the two experiences of the families that we heard this morning, which are not, in my experience, at all extraordinary—I think every person in this room, if you think through your extended family, has one such experience that you can easily point to, or even in your own family.

This is the typical situation we are facing now, where people that have good jobs, who are very competent, caring parents, can't negotiate the system. The system does not work.

We are probably going to end up not just tinkering with the system, we are going to have to do something fundamental that is going to make it a lot simpler and hopefully at least reduce the administrative end of the costs.

We are paying. When I talked about those 50,000 cases of measles, I don't think there are children, you know, seriously ill with measles and pneumonia that are at home. They are in the hospital. Somebody is paying. But it is a cost that we wouldn't have to be paying at all if the children had been immunized.

Mr. HOLLOWAY. I agree. The system is nearly broke. But I mean, what is the answer to it? I mean, it is not more government programs.

Chairwoman SCHROEDER. We are trying to find that.

Mr. HOLLOWAY. That is why we have a witness here. That is why I am asking him, if he can, to tell me. I mean, more government, you know, I don't think we are the answer to it. Tell us where you think that we can, other than cutting paperwork?

Chairwoman SCHROEDER. I think the time has about expired, unfortunately. We have some other people who want to ask questions.

Mr. HOLLOWAY. Well, I would like to ask Dr. Johnson a question, if I can.

Chairwoman SCHROEDER. Okay. Certainly.

Mr. HOLLOWAY. Because I don't understand basically what the policy is or what we are really—how his testimony almost fits into this whole thing.

I mean, I don't know basically where we are coming from with adolescents if we—and you say you missed the part with the parents involvement in it. I don't know, do you counsel adolescents on absence from sex, smoking, drinking? To what point do you fill—I guess yours are typically, you said, about 12 years old, that you have a typical child come into your clinic, Dr. Johnson.

Dr. JOHNSON. Well, I am not sure of your question, Mr. Holloway.

Mr. HOLLOWAY. Well, I am just wondering, basically it sounds to me like, you know, almost you have another agenda or policy that we are not even——

Dr. JOHNSON. Well, I was asked to come and speak to the committee about the barriers that adolescents face to health care. And also I was asked to outline, discuss The Door, which is an exemplary comprehensive program for adolescents in New York City.

Parents are not excluded from health care and there are a number of important health care issues that adolescents have. Adolescents move into a time period where they begin to experiment with sexual activity and therefore their sexual activity becomes an important health care issue. Adolescents move into a period in their lives when they become exposed to substance abuse and therefore substance abuse becomes an important issue.

So the health care provider, if he or she is going to take the responsibility of assisting this young person in maintaining their state of healthiness, must consider all of these issues. And those issues are both physical as well as psychosocial.

I am not surprised that you don't understand this approach, because this is an approach which is very different than our focus on catastrophic care.

The health care system or the insurance system began as an approach to pay for surgery and it then extended to a system to pay for very serious illness. But preventive care is something that is a movement that is relatively new.

The health care industry has begun to realize the importance and the savings that can be realized with preventive care. But we really don't know how to adequately pay for preventive care.

Now with reference to your other question, I recommend that you look at the Oregon Health Plan. I am sure you are familiar with that. The Office of Technology Assessment has either released or soon will release a study of that plan. And it is a revolution in the way to finance health care.

And I had some very serious concerns about the plan at the beginning, especially the way that it will respond to health care needs for children and for adolescents. But we do need a revolution in health care. We cannot fix the existing system.

And this plan, this issue must be looked at by Congress, your colleagues, as just as important as a war in the Persian Gulf. Because if we don't address it now, it will bury us by the end of this century.

Mr. HOLLOWAY. Maybe I misunderstood what you said, but it sounded to me like you were leading to the fact that adolescents should have their own card, should have their own ability to go down and buy their own prescription drugs without parental consent or anything.

Dr. JOHNSON. I did in fact say that. Well, the law allows an adolescent, for example, in every state to consent for the care of a sexually transmitted disease. Yet the young person who saw me in my clinic last week, although he could come to the hospital and sign for that treatment, could not fill the prescription for that disease because he didn't have a card.

Mr. HOLLOWAY. I would love to continue but I will stop.

Chairwoman SCHROEDER. Thank you. Congressman Durbin.

Mr. **Durbin**. Dr. Johnson, let me follow up on that. And I am trying to reconcile in my own mind some conflicts here, and I think Mr. Wolf alluded to them earlier.

In my home town I tried to get together with some groups and talk about low birth weight babies and teen pregnancy and infant mortality, and finally found ourselves talking about everything. It all came in. You just can't isolate these problems.

We found, when we could get doctors who would take Medicaid patients, young women who were pregnant and needed prenatal care, that we had to find a way to virtually drag many of these women in for prenatal care. It wasn't just a matter of telling them how important it was. They would nod and say yes, and still wouldn't keep the appointments. We had to pound it into them to get them to come in.

And when the babies are born, and I visit a day care center across the street from the prenatal clinic for a lot of the families that don't have the resources for private day care—it is kind of a semi public day care center—the people throw up their hands and say, what a problem we have. They hate weekends because on weekends these parents take these babies home and dilute the formula, after being told over and over not to do it, take the disposable diapers off and hang them over the shower curtain rod and let them dry out and use them again. And the babies come back with all sorts of diaper rash problems that the day care center tries to cure during the week.

What this brings me to is that a lot of these young people need to be told they have to be responsible for their own bodies and their own health. But you are dealing with a level where there is a lack of knowledge and a lack of maturity.

And I just wonder, following up on some of the things said here, how far can you go, though? I mean, you must run into this in your practice all the time. How far can you go to entrust a young person with that judgment, knowing full well that they are still going to need advice and counsel and a helping hand?

Dr. **Johnson**. Well, is it a problem with the health care consumer or is it a problem with the health care provider and the way the provider delivers the health care?

At The Door in New York City and in our clinics at the New Jersey Medical School, we make the adolescent the primary consideration of that care and we make them responsible.

Young people are told that they should come back every six months for a health care visit. And they come back every six months for a health care visit. They make their appointments. They take the responsibility to take their medications. We have a compliance rate that approaches 95 percent in a clinic in an inner-city hospital that is very difficult to get to.

So it can be done. But it has to be done keeping in mind who the adolescent is and how you must correctly approach the adolescent.

If you approach the adolescent, whether it is a pregnant young woman, with the assumption that she is dumb and stupid and can't take care of her baby correctly and therefore you have to preach to her and tell her everything to do, I will bet you she doesn't show back up at that clinic.

But if you approach this young woman and say, you are an individual to be valued, you are an individual who can and wants to take responsibility for your own care and the care of your infant, and we are here to help you do that and we are here to listen to you tell us how we can best help you do that, you will get them back.

But we don't do that. We are very punitive in our approach and we are very unenlightened about the way we should look at adolescents and their relative maturity in this country in many issues. The health care system is only one of the systems where we have this ambivalence.

Mr. DURBIN. Madam Chairlady, I hope we have a chance to visit this clinic. We have done that with the committee from time to time. I would like to see this in action.

My last question to Ms. Brown: You talked about the three month waiting period. Now far be it from me to rush to the defense of insurance companies. I don't want to do that. It kind of chafes against my own philosophy and nature. But how do you deal with the adverse selection situation?

If you have got a person who is critically, terminally ill, who can walk in off the street and sign up with a health insurance company and be covered from day one, how do you answer the criticism of the health insurance industry that that will bankrupt them overnight?

Ms. BROWN. This is a classic example of how we have competing issues that we are going to have to resolve. On the one hand, we have an industry that has its own requirements for profit making and for management, and on the other hand, we have health care needs. Clearly, in certain instances, the two are inconsistent. I think that is actually the word I used. We are going to have to decide which is more important, or we are going to have to decide some way to help the insurance companies finance that risk.

But if we say to women that one of the ways you can help yourself and your baby is to get early prenatal care and then simultaneously permit insurance companies to restrict access to care, we aren't giving a consistent message. Obviously, we need to resolve such inconsistencies.

My own bias, because I am most interested in healthy pregnancies and healthy children, is to find a way to reduce waiting periods. But that may require some different approaches to insurance regulation. It is a tough call. But we have two competing interests here that are at their heart irreconcilable.

Mr. DURBIN. And that may lead us to some of the general reform programs you talked about.

Ms. BROWN. I would think so.

Mr. DURBIN. We may not be able to deal with some except on a piecemeal basis. Though I have to say President Bush, as well as all Democratic plans that I have seen before Congress, deal with pre-existing conditions, and they should.

Ms. BROWN. Yes. Distress with pre-existing condition exclusions is one of the messages that is beginning to come through loud and clear to the Congress.

Mr. DURBIN. My closing comment, based on a question I asked you earlier, is over the weekend I met with a state senator from

Minnesota who explained to me what she had been through in the promulgation of their plan that was passed a couple of weeks ago.

It was curious to me, having been around this place for a few years, that they mustered the political courage in Minnesota to impose a tax on cigarettes and on alcohol, and a two percent tax on all providers of health care, to come up with the money to fund a plan to set out to do something in their state. And we seem to be just frozen in the headlights here when it comes to the word, taxes. We can't deal with it, even if it is for the solution to a national problem which most Americans concede needs to be solved.

The states are going to shame us, I am afraid, as they show the initiative and move forward and the Federal Government is just frozen in its track.

Ms. **Brown**. One of the reasons that so many of us want to get issues of maternal, child health and adolescents' health clearly before the Congress now is that we understand, in part, the kind of turmoil that will ensue, and the kind of guts it is going to take, for the Congress to come to grips with health care reform and cast a vote.

We are worried that so much political capital will be spent in getting something passed that the capacity after the fact to say, oh, yes, we forgot about immunizations or we didn't do anything about nurse midwives, and, oh, what about the lack of obstetricians in underserved areas, etc., will be minimal. We will all be in a state of "compassion fatigue" and "policy fatigue," and the door may well be shut except for a few technical amendments.

That is why we really want these issues out now, so that the course of Title V and the position of the public health system, for example, are taken up as part of the main debate and not something addressed inadequately, after the fact.

Mr. **Durbin**. A good point. Thank you very much.

Chairwoman **Schroeder**. Thank you. Congressman Walsh.

Mr. **Walsh**. Thank you, Madam Chairwoman. I have really enjoyed the testimony that I have heard today. We are all talking about this issue and it is good to see it from a child's perspective.

I would like to ask a specific question. We took the liberty of sending, I believe, all of you—but we may not have sent one to Ms. Brown because we didn't have her name for the witness list—a bill that I have in regarding mandatory testing, auditory stem testing for infants, for all newborns born in the United States.

The idea for that is to, in a preventive sense, determine what hearing disabilities there are and react to them at an early age, so that we are not spending larger sums of money down the road to deal with that disability. Testing for infants would be mandatory. I don't believe we have ever done that before. And it would require this test be paid for by private health insurance or government insurance. The test is relatively simple and relatively expense, the $25 to $30 range.

If you have a thought on it, please feel free to make a comment on the idea of this approach and the mandatory nature of it.

Dr. **Nelson**. Mr. Walsh, your office did send me a copy of the legislation. I think we are moving rapidly toward trying to do what your legislation calls for in practice, in that the technology has developed within the last few years to make this a much more practical thing to do.

Most hospitals and centers that deliver infants now at least are screening infants that have some risk, known family history or they have had some neonatal problem. But that only detects, at best, maybe half of the infants that have significant hearing loss. So unless you screen all, you are going to miss the other half.

Even at $30, though, let's say, times four million births in the United States, you are talking, if my arithmetic is right, about $120 million of costs.

Mr. **Walsh**. That is right.

Dr. **Nelson**. And I think the reluctance in a lot of areas has been just how that cost will be allocated. If legislation can establish this as a preventive measure, as an early identification measure, and those costs are distributed among insurers, this screening will be a good thing.

If it ends up being solely a public sector responsibility, in the current climate I don't think it will easily happen, because the dollars aren't there to do it.

Mr. **Walsh**. Yes. We wouldn't expect it to be that. We would expect a public/private mix.

Dr. **Johnson**. I also received the draft, Mr. Walsh. I am also concerned about the costs and I wonder what we will lose as a result of this testing, because I am sure something will lose if it is going to cost over $100 million, and then what the ultimate gain is.

The other issue is the timing. The bill does call for newborn and I must admit I treat only kids above 12. But I think that it might be more effective if it were done past the third month, or during infancy, rather than the newborn period, three to six months. And the American Academy of Pediatrics is looking at this issue and there are recommendations from the academy on infant testing for hearing loss. And you might want to contact them, the Committee on Pediatric Practice specifically, and look at their recommendations. But they do focus on infant rather than newborn testing.

Mr. **Walsh**. I will do that. Thank you. And thank you all for your comments.

Just one last point. Dr. Johnson, in your approach to adolescents—I have two. I have a 15-year-old and a 12-year-old who is about to become a 13 year old.

Dr. **Johnson**. God bless you.

Mr. **Walsh**. I pray for strength every day. I have, thank God, a very good relationship with them, and my wife does, too, and we work at it.

I am better able to communicate with my children than my parents were with us, and I think there is a generational difference in this country for sure.

I would feel a little uncomfortable with your approach in that it seems that while your intent is to give the adolescent more decision making in terms of not only their own health but in the direction that they want to head in all their decisions.

I would want very much to be involved in that process, as a parent. I would have no objection to you spending five or ten minutes with that child alone to discuss their health. But if they were to be treated for either a venereal disease or some other ailment, regardless of whether it was sex related or anything else, I would want very much to be part of that discussion.

A child that is homeless, that is without parents, obviously there is no other way to go. But in other cases I would urge that the parents be encouraged to take part in every aspect of that individual's health, not only because I think parents help children make wise decisions, but also because it keeps the communication open.

If the child feels that there is another adult in their life who is directing them away from their parent, I think that may cause problems.

Dr. Johnson. I absolutely agree with you, Mr. Walsh. And in my experience, just about all the teenagers in my practice have active parental involvement. And it is usually the parents who direct their children to our clinic. So The Door is an exception with that. Young people come to The Door on their own.

But just last night, for example, there was a young man with a strep throat, and I treated him for that. He wanted me to call his mother and tell his mother about it. And he is 16, actually 17 years of age.

So there is not a schism that we create between the parent and the adolescent. But let me enlighten you on the issue of sexually transmitted disease.

Now if our 15-year-old does have a sexually transmitted disease—and I believe you are from the State of New York, but it doesn't matter what state it is—that adolescent is enfranchised for the treatment of that disease. The health care provider not only can provide care for that young person without parental involvement and parental notification, the health care provider must provide that care. And the health care provider must have the adolescent's permission to inform anyone else about that diagnosis.

Now that is an existing state law. It varies slightly from state to state. But state legislatures have given adolescents these adult-type rights for the treatment of sexually transmitted diseases, pregnancy and substance abuse in all states.

And there was a very important recognition that young people would very often refuse to receive care because they didn't want parents to know.

The 16-year-old boy I told you about who didn't get his doxycyclin because he couldn't get his card from his mother, has a very good relationship with his mother and his father, but he didn't want them to know. He didn't want them to know that he was sexually active. Although the parents—his mother puts condoms in his underwear drawer once a week and she very well knows he is sexually active, he didn't want her to know that he had this disease. And because of that, he went a week without receiving treatment for it because he was just afraid of telling her.

Mr. Walsh. That is a very unusual situation that you just described and I just think there is a real communication breakdown there, and perhaps further, even a moral breakdown there, in my mind.

Dr. Johnson. Well, I disagree. The fact that teenagers can't communicate with their parents, are afraid to communicate with their parents on one issue, an issue as intimate as sexually transmitted disease, doesn't mean that there is an overall communication gap or breakdown between parents and children.

I think we make a mistake when we focus on very embarrassing, highly personal issues and say that if you can't communicate on those very embarrassing, highly personal issues, then that means that the whole relationship is no good. That is just not true.

Mr. WALSH. Well, I guess we are getting into philosophy now. But a mother who puts condoms in the top drawer for her 16 year old son on a weekly basis I think is making a tragic mistake.

Dr. JOHNSON. Well, I disagree with you. I think that indicates that the mother has communicated with her son, realizes what her son is involved in and wants her son to be protected. It is something that many, many parents in America do.

Many parents recognize the fact that their children are sexually active. At 16 in this country, 60 percent of boys are sexually active.

Mr. WALSH. And they are not willing to show the courage to stand up to their own child, that could be a fatal mistake for them.

Dr. JOHNSON. Well, we disagree, Mr. Walsh.

Mr. WALSH. Yes, we do.

Chairwoman SCHROEDER. Well, we have kept the panel way beyond when we should, and I have a thousand questions. But I promise I won't do that to you.

I do want to say I think it has been very, very helpful to look at this. And as Ms. Brown said, our fear is we will do something and then suddenly say, oops.

And of course, the one I think we are most apt to say oops about is adolescent medicine, because there are very few advocates out there for adolescents. And it is such a sensitive issue that you instantly get into these very difficult discussions.

Dr. Johnson, I just wanted to ask, your specialty is very, very small, isn't it?

Dr. JOHNSON. Well, adolescent medicine is part of pediatrics. Pediatrics now, as you know, is the care of infants, children, adolescents and young adults. So we go someplace up to 21 to 25 years of age.

Adolescent specialists are persons who have done a fellowship in this area. There are roughly three to four thousand practitioners now. And this specialty will be a boarded formal specialty by 1993.

So it is relatively small but most pediatric departments in this country have a section on adolescent health care.

Chairwoman SCHROEDER. I thought your putting it in historical context, that we don't think about it because we don't think of catastrophic things that normally happen to adolescents, but preventively it is probably the age where you can do the most prevention.

Dr. JOHNSON. Absolutely, yes.

Chairwoman SCHROEDER. Long term. Well, I thank you all.

The record will be open for two weeks if people think of more things. And I apologize again for keeping the panel so long. But I think it is because you had so much to say and we enjoyed it.

Thank you very much. And with that, the hearing is adjourned.

[Whereupon, at 11:45 a.m., the select committee was adjourned.]

[Material submitted for inclusion in the record follows:]

Prepared statement of Hon. Mike Bilirakis, a Representative in Congress from the State of Florida

Madam Chairwoman, I want to commend you for holding this hearing on health care reform and how women, children and teens would be affected by current health proposals. Throughout my district, there are continuous debates on health care reform because most Americans have very strong opinions about what should be done. I receive hundreds of letters each week from my constituents, expressing their dismay about rising health care costs, unaffordable health insurance, overpriced prescription drugs—the list goes on and on.

I, too, am deeply concerned about newborn infants and the large number of pregnant women who do not receive prenatal and postnatal services. I serve with Roy Rowland as the co-chairman of the Task Force on Infant Mortality for the Congressional Sunbelt Caucus and we have found our Nation's infant mortality statistics are dismal. Part of the reason for this is the inaccessibility of health care services.

To resolve the problem of access, I have introduced legislation with Congressman Rowland and a number of my colleagues from the Sunbelt Caucus that is designed to expand access to obstetric services, particularly in medically underserved areas. H.R. 3089, the Access to Obstetrical Care Act, will provide funds for a number of Medicaid demonstration projects designed to increase access to obstetrical care for women in medically underserved areas.

These demonstration projects will enable States to design and implement projects sensitive to their particular needs. Improved access to health care will result, hopefully, in lower infant mortality rates.

Unfortunately, Madam Chairwoman, as far as health care reform is concerned, we've got a mess on our hands. I believe it is the joint responsibility of Congress and the administration to clean it up. Our health care system isn't improving—it is just getting worse. Since I've been in Congress, we have done nothing but apply Band-Aid solutions to a problem of devastating magnitude. Something has to change or the health of our citizens, particularly those who cannot afford the luxury of private health insurance, will continue to decline.

It is encouraging to me that so many of my colleagues are beginning to recognize that this is a serious problem and want to do something about it. Almost forty health overhaul bills have been introduced during the 102nd Congress, a bi-partisan Health Care Caucus on National Health Care has been created, and House Minority Leader Bob Michel formed a task force to develop a health care package to address national health care concerns, so there is some movement in Congress.

As a member of this task force, I am pleased to say that a legislative package on health care reform will be introduced in the near future. Health care reform is the issue of the 1990's—I, perhaps am an optimist, but I believe that we will be able to develop some sort of a national health care strategy during this decade.

It is my hope that we will be able to develop a strategy that will involve both the private and public sector in a partnership, yet still encourage competition. I am not in favor of adopting a socialized health program, and I believe we must be cautious of heading in that direction.

However, by creating a national health care strategy, sacrifices are going to be required by everyone—patients, doctors, hospitals, and insurance companies all will have to make concessions. I believe it can be done so that everyone will have some degree of satisfaction.

I do want to remind my colleagues of a similar scenario from a few years ago—catastrophic health care. Before that legislation became law, almost every senior citizen was behind the bill, and when it became law, reality began to set in. One of the biggest mistakes made, in my opinion, was that not enough time was spent studying the legislation, and the average citizen did not take the time to fully educate himself or herself about the bill. Once it became a reality, America began to wake up.

Creating good, practical health care reform legislation will require lengthy discussions among Members of Congress, the administration, the public, health care providers, and health organizations. Madam Chairwoman, I believe we are on the road to resolving this problem. I look forward to hearing from our witnesses, and thank you again for conducting this hearing.

PREPARED STATEMENT OF ELAINE H. WALIZER, CHAGRIN FALLS, OH

My husband and I are the parents of a daughter, Laura Elizabeth, who was born in 1980 with major birth defects, including a serious heart defect. I have been asked to make a statement for the Select Committee on the issue of health care for children and the need for health care reform. I believe our experiences over the past twelve years have given us a unique and piercing perspective of the gaps in our system of health insurance and health care delivery, and of the stresses that these gaps create for families already struggling to develop a stable, nurturing family life in the face of chronic illness and disability.

Our daughter's serious medical problems were manifested late in her second day of life. We were fortunate in living near a major medical center; neonatal intensive care, surgery, medications, and caring professionals saved our child's life. By the time she was released from the hospital, we had learned that Laura has a chromosomal abnormality known as Turner's syndrome. It is the source of her heart defect, which required several surgeries, the last of which left her partially paralyzed. (Management of this physical disability commands much of our concern, our resources, and our adaptiveness.) Laura has some other sequelae of Turner's syndrome: kidney malformation; eye muscle imbalance; maladaptive structure of palate and jaw; a growth disorder; missing ovaries; learning difficulties with visual/spatial and visual memory tasks despite high intelligence and a "very superior" verbal IQ. Women with Turner's syndrome are also known to be at risk for diabetes and thyroid disorders. For normal development and optimal health, girls and women with TS require hormone replacement.

Laura is one of many children who are surviving birth defects and serious illnesses; we expect that she will grow to adulthood and live a full life span. We know, however, that she will need to monitor her health carefully, that she will always require the care of specialists, and that she will need medication and hormone replacement throughout her life.

We all grapple daily with the demands of living with her disability and her medical needs--and we are rewarded with the joy of her achievements. Yet daily we parents worry about Laura's future; the day is coming when she will no longer be covered under the umbrella of our health insurance, and Laura is uninsurable. She won't be able to buy a policy at any price under the present system. Our daughter is intellectually gifted; who can know what she will contribute to the world? If, that is, she is allowed to go out and work in it. Many employers would rightly conclude that to hire her would be to raise the cost of company health insurance so high that she would be a liability as an employee. We wonder if Laura's bodily life was saved only to reveal that her spirit would be broken.

[We have a further worry in that there are no legal safeguards for Laura or the many other citizens who have gene-related predispositions for developing serious health difficulties. The Human Genome Project, rather than being an exciting exploration on the frontiers of medical/scientific knowledge, raises for us the specter of prejudice and discrimination. Based on the mere possibility that Laura might develop further health problems associated with her identified condition, insurance carriers are potentially free to reject her application for a wide range of coverages, (including health, life, disability, and accident insurance.) There are currently no legislative protections against abuses of biotechnology such as the use of genetic testing to eliminate "high risk" applicants.]

Given that the birth of offspring alters the life of any couple, our first child's birth nevertheless changed our lives more painfully and drastically than we could ever have expected. Due to complications of pregnancy, I had been forced to take an unpaid leave of absence from my teaching position; no disability protection was available. We maintained our health coverage by paying premiums to my employer, the county office of education. Because of Laura's serious problems, which continued to worsen over the course of her first year, I was forced to use up my considerable accrued sick leave and finally to resign my position permanently. One effect of Laura's birth defects, then, has been the unwanted and unplanned end to my career (after a graduate degree and nine years of teaching.) The

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reality was that my husband's greater earning power and our daughter's great need for extensive ongoing care dictated our decisions during that time. While the outcome ultimately might have been the same, the lack of a family leave policy meant that my outside employment ended; my husband gave up self-employment and sought a position with a company which would provide health care coverage. He was a hostage to our desperate need for health insurance.

We found that we were geographical hostages as well. The necessity of obtaining frequent care from a growing list of pediatric specialists made it imperative that we "choose" to live within easy reach of a major medical center. This has meant, literally, that my husband has from time to time backed away from desirable potential employment because it was simply too far from appropriate medical care for our daughter. (The level of care which Laura has required has varied; at one time, she had three appointments weekly for medical care or related services. Currently, we average three office visits to specialists each month, with weekly therapeutic/ recreational activities in addition.)

Supposing that my husband's health care insurance actually covered the expense of a major health problem would be a significant error. Policy exclusions always seem to strike where they hurt the most. Our daughter wears plastic orthoses (braces) on her feet; these have to be custom-made and adjusted from time to time. Her shoes must be purchased to accommodate the orthoses; the necessary width, over-ankle height, and lacing is only found in the most expensive leather tennies, which are naturally "not a medical expense." They also have to be modified by the orthotics laboratory, at a minimum cost of $47; this modification is not a covered expense. Laura seldom outgrows her shoes; she wears them out faster than that. Then we find $100 for another pair. This is just one of a host of examples from which I can choose.

Further, well-child care, the pediatric first line of defense in preventing potential (or additional) problems from worsening, has not been a paid benefit under most policies we have had. Some of the most important early-childhood immunizations cost approximately fifty dollars each. We never questioned having these for our children, so we just paid for them; but we can well imagine that other parents would be choosing between immunizations and food on the table. Dental and orthodontic care, for which we have no coverage, is a similar matter.

While many medical expenses are covered, we also face an annual deductible amount and our "patient share," which is typically 20% of an office visit charge. (Laura's highly-trained caregivers typically charge from $60-$95 per office visit.) If we seek care from a provider who does not have a UCR (usual, customary, reasonable) fee agreement with the insurance company, we are responsible for any amount in excess of the "allowed" fee, (usually $39 for an office visit.) These extra amounts are not credited as part of the deductible; they are simply out-of-pocket expenses in addition to our "patient share." The expense to us for medical care for our son, who has no major health problems, is not excessive; the expense to us for medical care for our daughter, who has chronic medical problems and a significant physical disability, is another matter, *despite* the fact that we have had "good" coverage.

There are many hidden costs to chronic illness and disability. Unless I wish to drag Laura's younger brother (born in 1983) along on her many appointments, I must pay for child care. It's certainly not covered by health insurance, and it's hardly deductible as a medical expense under IRS rules. Child care deductions on federal taxes are for *employed* parents. Another example: we purchased a used bicycle for our son, Nathaniel, for $20; we wanted Laura to enjoy the physical and recreational benefits of biking, too... and were fortunate enough to find a "bargain" catalog with an adult three-wheeler for $278. (A portable model, which might broaden Laura's recreational horizons, costs $500.) This sort of purchase could be argued as "adaptive equipment" on a tax form, but changes in tax law during the past decade also punish us. When the *allowed* medical expenses must exceed 7.5% of taxable income, our relative financial comfort means that we cannot itemize those deductions. The hidden costs "don't count." Our extra medical costs mainly reduce our disposable income and potential savings.

One must not suppose, further, that health insurance carriers are cooperative in paying covered expenses. I struggle constantly with our insurer over incorrect denial of benefits, delayed payments, and excluded diagnostic categories. I shudder to think what happens to families who don't have the necessary energy or comprehension, and who thus fail to receive benefits to which they are entitled. An additional burden of heavy medical expenses is the battle to have bills paid properly and in a timely fashion by the health care insurer.

The lack of a single-payer system has meant, repeatedly, that our child has gone without treatment while we satisfied "pre-existing condition" clauses or waited for an open enrollment period. Specific example: Laura's short stature and below-normal growth rate gave her a predicted adult height of 4'6"--another handicap! Her Stanford endocrinologist was ready to begin treatment with rDNA human growth hormone. My husband changed employers, and we moved to Ohio. We had to wait six months before Laura could see a new endocrinologist, six months during which she could have been treated and could have been growing had her care not been interrupted.

One method by which families often "control" the high costs of raising a child with health problems is by entering studies. In our case, we considered that we were contributing to the body of medical knowledge and in return receiving free treatment for Laura. This works out well, unless, of course, the double blind study places your child on the placebo. In our case, either Laura was indeed on the placebo or the dosage in the study was too low to benefit her. We exited the study after nine months. The current cost of her hGH is approximately $4000 per month, much of it profit to the drug company. Office visits and laboratory tests are in addition to this amount.

We have received other free care in the past: when we resided in Dallas, the Texas Scottish Rite Hospital provided a wide range of services at no charge. The facility is beautiful and elaborately

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equipped and staffed, the drawbacks of this type of "closed" facility emerged slowly over time. We did not have free choice of physicians, and sadly we were exposed to some who could never have attracted and kept patients based on their interpersonal and communicative skills; a captive audience/ clientele was their only hope. Continued conflicts over care delivery--refusal to allow parental presence during invasive tests; denial of access to records; lengthy and harmful delays in obtaining equipment and bracing; lack of physician choice--eventually led us back to the fee-for-service medical market and the ongoing battles with the health insurance companies.

We also have had the experience of belonging to an HMO. Managed health care plans are perfect for ordinary families whose members enjoy fairly good health--a piece of luck they are probably unable to appreciate fully. The general population needs a minor range of services that is easily provided in the fashion of HMO's. But a child with serious difficulties requires the care of highly-trained pediatric specialists, and these are not found in managed care programs. (In one instance, we were sent to a member "specialist" who was not Board-certified and whom we would never have selected as a caregiver for our daughter.) Many special services are contracted from larger facilities such as teaching hospitals, and they remain costly. Thus, the family whose child requires these expensive "extras" finds itself subtly harassed; the services are grudgingly approved and the process of obtaining care is prolonged and troublesome each time an appointment is required.

I am not painting a fictional worst-case scenario; I am describing something that we have experienced first-hand. Once, after lengthy negotiation (during which we were supported by our very patient and dedicated pediatrician and by the HMO dermatologist), our HMO reluctantly agreed to allow our daughter to be seen by an expert at an area medical center. However, the HMO refused to mail me the authorization letter; I was required to pick it up in person since they were "making a special provision." At that time I was still recovering from the Caesarian section birth of our son; I had to pack up our infant, our barely-ambulatory daughter, and drive to their distant offices or risk losing the opportunity for our daughter to receive care. Was that reasonable or was it simply mean-spirited harassment?

I hope you understand that there is much more I could tell, were it not for limitations of space and the press of time. We are far from the only family experiencing these stresses; in fact, in some respects we have gotten off lightly. My wide acquaintance with other families, through our membership in support groups and a broad personal network, tells me that we are not unique; many families are burdened by the problems in our current systems of health insurance and health care delivery.

I wish to make clear that we do not see our daughter as the burden. Laura makes a positive contribution to our family; we have great expectations for her and for ourselves as a family. We have grown personally and found meaning and purpose in our struggles despite many difficult days. We know our strengths; we feel competent to direct our lives and make our choices. We feel connected to many fellow citizens whose courage, fortitude, and love sustain them daily as they nurture their hurt children. All of us want full citizenship for our children as they participate in American life--both our children with the gift of health and our children with disabilities.

Ironically, President Bush came to Cleveland to unveil his health plan, and he cited the success of programs such as COSE, which provides insurance for small businesses and controls costs. COSE is one of the insurers who has rejected us! Their "success" is based on their policy of cherry-picking; they simply refuse to enroll anyone with major health problems. If we did not need health care coverage, we would of course be accepted.

We do not believe that our country lacks the resources and the ingenuity to revolutionize our system of national health care. The basic goals must be that of promoting wellness and of caring for all of our citizenry. The quality of medical care potentially available in the United States is second to none, but currently it is ruthlessly rationed according to ability to pay. In addressing this issue, we cannot afford partisanship; we seem only to lack a leadership with the will to devise a plan and then put it into practice, refining it as we gain experience.

Presidents, senators, and congressional representatives are elected by the people, to enact the will of the people, and to govern for the benefit of the people. Write a plan that doesn't burden small businesses, that prevents corporations from taking in the windfall from unpaid retiree liability, that promotes cooperation, controls costs, and reduces the burden of administration. Government is not too big, it's too serving of selfish interests. Time for it to serve its citizens!

PREPARED STATEMENT OF ROBERT H. SWEENEY, PRESIDENT, THE NATIONAL ASSOCIATION OF CHILDREN'S HOSPITALS AND RELATED INSTITUTIONS, INC., ALEXANDRIA, VA

NACHRI -- the National Association of Children's Hospitals and Related Institutions -- is pleased to submit this statement for the record of the Select Committee's May 5, 1992, hearing, "Health Care Reform: How Do Women, Children, and Teens Fare?" NACHRI strongly commends the committee for addressing an issue of such great importance to both the health of children and their families today and the future of the nation tomorrow.

Background

NACHRI is the only national, voluntary association of children's hospitals. It represents more than 100 institutions in the United States, including free-standing children's hospitals, pediatric departments of major medical centers, and specialty hospitals, such as pediatric rehabilitation and chronic care facilities. Virtually all of the children's hospitals are teaching hospitals and research centers, and many function as regional referral centers for specialized care.

While they are best known as tertiary level hospitals providing highly specialized inpatient care for very sick, disabled, or injured children, children's hospitals are also major providers of outpatient care, including primary, emergency, and specialty care in ambulatory settings. Indeed, the typical children's hospital functions as the primary care pediatrician for the children living in the surrounding neighborhood, as well as the provider of specialized hospital care for children throughout the region with acute and chronic health care conditions.

In this statement, NACHRI speaks to:

- children's hospitals' support for health care reform;
- common themes among the growing number of health care reform bills;
- the importance of assuring health insurance for low income, working families;
- the importance of assuring a minimum health benefits package that reflects the health care needs of children;
- the need to recognize that several health care reform proposals seek to contain health care costs by extending to private insurance the use of the Medicare prospective payment system (PPS) rules, which are not designed to reflect the health care needs of children;
- the need to recognize that several health care reform proposals seek to contain health care costs by expanding use of managed care, which requires protections to ensure children's access to regionalized and specialized health care services when they need them.

Children's Hospitals Support for Health Care Reform

NACHRI strongly supports the efforts of Members of Congress to develop national policies that will ensure financial access to health care for every American. The children's hospitals are acutely aware of the need for such reform because of their roles as children's advocates, indigent care providers, catastrophic health care providers, and pediatric health care providers:

- **Children's Advocates** As advocates for the health and well-being of children, children's hospitals believe it is imperative that the nation recognize that more than 28% of uninsured Americans under the age of 65 are children, and that the growth in the numbers of uninsured is a direct consequence of the decline in employer-sponsored dependent coverage, as well as the increasing costs and restrictions on private health insurance to small businesses. Lack of health insurance limits children's access to health care, which jeopardizes their future health and well-being.
- **Indigent Care Providers** As institutions that frequently have historic missions of caring for all children and because of their inner-city locations, children's hospitals have become major providers of health care to the children of low income families. On average, a children's hospital devotes more than 40% of its care to children of families who lack private health care insurance and depend on either public assistance such as Medicaid or charity for their children's care.

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- **Catastrophic Health Care Providers** Because they are organized to care for the sickest of children and children with serious chronic conditions, children's hospitals see a disproportionate share of children who are uninsurable, regardless of income, because their health care needs exceed the limits of their parents' health care insurance or trigger pre-existing condition exclusions which prevent continuous health care coverage when their parents change employment.

- **Pediatric Health Care Providers** Children's hospitals exist precisely because the health care needs of children are so different from the health care needs of adults. And in caring for children, children's hospitals are acutely aware that the health care insurance needs of children are different, too.

Children's hospitals are not alone in their concern about the inadequacy of children's financial access to health care. Repeated public opinion survey research demonstrates that Americans are deeply concerned about the need for the nation to invest in the health of its children. In particular, national surveys have shown that a majority of Americans not only wants government to spend more for health care for all children but also would be willing to pay small increases in personal taxes in order for all children to have improved access to health care.

Common Themes in Health Care Reform Bills

There are now more than 50 Congressional proposals to reform access to health insurance and health care, plus the President's proposal and those of many private organizations and individuals. Their diversity is almost as great as their numbers, encompassing tax-based market reforms, reform of health insurance for the small business market, "play or pay" models, single-payer models based on the Canadian system or Medicare, and "managed competition" that relies on a version of managed care. As a consequence, Congressional consensus on overall health care reform has yet to emerge; indeed, it has not formed within each party.

Despite the lack of overall consensus, a number of common themes are apparent:

- bipartisan support for assuring health insurance for families of individuals employed by small businesses;

- bipartisan support for the principle of a minimum health benefits package for all insured, regardless of whether it is paid for by private insurance or with public assistance funds; and

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- support, in some quarters, for assuring cost containment, particularly through Medicare's diagnosis related group (DRG)-based prospective payment system (PPS) rules and through managed care.

Precisely because children's health care needs are different from adults', children's hospitals bring a special point of view to each of these themes.

Assuring Health Insurance for Low Income Working Families

In the fall of 1989, NACHRI conducted a one month survey of the uninsured admissions to 22 children's hospitals in order to take a "snapshot" picture of the uninsured children seen in these hospitals. The survey found that:

> Typically a child who is uninsured at the time of admission to a children's hospital is very young and has few siblings. At least one parent is employed, often for a small firm, and in either the service or the construction industry. Usually the parent cannot obtain insurance through the employer, but the family's low income makes private insurance unaffordable to purchase personally. It is not unusual for the child to need immediate hospitalization for emergent or urgent care. About half of the time, the child eventually is found to be eligible for Medicaid after admission to the hospital -- the younger the child, the more likely the child proved to be Medicaid eligible.

In general, this profile of uninsured children seen by children's hospitals is consistent with Current Population Survey data collected by the U.S. Census Bureau. But the subsequent identification of Medicaid eligibility demonstrates that eligibility for national health insurance or public assistance alone is no guarantee of coverage for, access to, or use of appropriate care. This is especially striking in light of the fact that more than 50% of the uninsured admissions identified in the NACHRI snapshot survey involved children in need of immediate hospitalization for emergent or urgent care.

According to Current Population Survey data, more than 70% of uninsured children live in poor or near-poor families with incomes less than 200% of the federal poverty level. These are families which are most vulnerable to moving in and out of the work force. These low income families also are the most likely to live in medically under-served communities where health care services are unavailable, regardless of the insurance status of the families.

Insuring access to appropriate health care for these children will **begin** but not end with guarantees of health insurance or public assistance.

Assuring a Minimum Benefits Package

A minimum benefits package that makes sense for adults will not necessarily make sense for children, since children have different health care needs from adults. For example, Medicare for the elderly is often cited as an effective model of public health insurance, yet its benefits, co-payment, and reimbursement are not designed to reflect the special needs of children. The table attached to this statement illustrates the striking differences in health care utilization by children and elderly adults.

Compared to elderly adults, children use less of both ambulatory and acute health care. They have far fewer hospital admissions, shorter inpatient stays, fewer physician visits, and much less long-term care. When they do use health care, children are more likely to use ambulatory and primary care than are the elderly, because children have basic preventive health care needs that are critical to their future development and different from adults' preventive health care needs.

As a consequence, the minimum benefits package which Medicare provides would be inappropriate for children. Medicare emphasizes acute care over primary and preventive care, both in benefits covered and in co-payment requirements.

For example, for children, immunizations, preventive dental care, developmental assessments, and anticipatory guidance, as well as medical, vision, and hearing screening are essential to prevention and early treatment of conditions that otherwise could cause significant morbidity and mortality. However, since they either are not indicated for the elderly, or can be less critical for this population, Medicare does not cover such services.

Similarly, Medicare Part B deductible and co-payments would be even more of a barrier to children's use of primary and preventive care than they already are for many of the elderly. Even for acute care, Medicare's co-payment requirements would need to be adjusted, because they are related to the cost of the first day of inpatient care. By tying deductibles to the cost of the first day of hospitalization, Medicare would force the families of children, who on average have shorter hospital stays but higher per diem costs than adults, to pay a proportionately larger cost for hospitalization. The impact of these co-payments on the families of children is especially significant, since children -- as the single largest group of poor Americans -- are especially vulnerable financially.

A basic benefits package for children must employ co-payments so as to encourage primary care, reflect the limited resources of young families, and build on the principles of the Medicaid Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program.

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Assuring Cost Containment Through Medicare Payment Rules and Managed Care

Two of the most frequently mentioned methods of health care cost containment are reimbursement based on the model of Medicare DRG-based prospective payment and managed care. However, without adjustments for the requirements of pediatric health care, each can be inappropriate to ensuring the continued availability of services children need.

Medicare Payment Rules When hospitalized, children require more intensive staffing -- to meet both their developmental and health care needs; more specialized health care -- to meet their different health care needs; and more space and physical resources -- to meet their families' needs as well as their own. As a consequence, the full resource needs of efficient and effective inpatient hospital care for children cannot be reflected in a reimbursement system based on average health care costs reflecting adult health care needs.

In particular, Medicare's DRG-based prospective payment system (PPS) is inappropriate for pediatric hospital care for several reasons:

- Medicare DRGs (diagnosis related groups) -- as a method of case-mix classification -- do not distinguish sufficiently among the resource demands of treating different pediatric diagnoses. (For example, the Medicare DRGs often do not distinguish between complicated and uncomplicated diagnoses for children the way they do for adults.)
- Medicare cost accounting principles fail to reflect the higher costs of pediatric hospitalizations, because they are based on general hospitals' cost transfer from pediatric to adult patients. The Medicare cost report averages adults and pediatric health care costs; it does not distinguish between the two.
- Medicare outlier policies fail to reflect the much higher incidence of high cost and long stay cases among children than adults, resulting from children being more likely to become sicker faster and to need intensive care more often when hospitalized.
- Medicare reimbursement for medical education and capital was not designed to address the specialized training required by pediatric nurses, physicians, and technicians and the more intensive facility needs of children.

Last summer, in its annual update of the Medicare DRG-based PPS, the Health Care Financing Administration noted:

> ...(T)he prospective payment system, and the DRG classifications in particular, are based on Medicare data and are designed for the Medicare population, that is, the elderly and the disabled. Therefore, changes and modifications that we make to that system may not always be appropriate for a younger population, such as the one treated most often in children's hospitals. (Federal Register, August 30, 1991, page 43211)

NACHRI is encouraged that several bills that would expand use of the Medicare PPS rules to private insurance do recognize the need for adjustments of those rules to reflect the needs of children in general and the patients of children's hospitals in particular. But these bills often defer to the discretion of the Secretary of the Department of Health and Human Services determination of the type and extent of such adjustments, if any.

There are many problems raised by proposals to extend Medicare payment rules to private insurance. Congress should not adopt such a policy without first engaging in a thorough assessment of the impact of such a policy, as is proposed in the Senate-passed small business market reform legislation. And even with such research, Congress should require any policy based on Medicare payment rules to:

> reflect modifications of the Medicare payment system and payment adjustments adequate and appropriate to meet the special hospital inpatient resource requirements for children, with updates and rebasing determined through the use of pediatric-specific inpatient data; and provided further that such payment shall be developed on a hospital-specific basis for hospitals whose inpatients are predominantly children.

Managed Care As a result of their missions of service to children, children's hospitals embody many of the principles underpinning managed care. They seek to avoid hospitalization whenever medically possible, because it is in the best interests of a child' development. They value the importance of coordination of care because of their extensive experience in working with children who often have highly specialized and challenging conditions. And because they see in their emergency rooms the consequences of the inability of families to obtain primary and preventive care, children's hospitals have become major proponents of primary care, both in organizing primary care services and advocating preventive care in their communities.

However, children's hospitals also know from their experience that if driven only by cost containment managed care can reduce, rather imrove access to necessary care, especially for children with special health care needs. In order to serve the different health care needs of children, managed care plans must ensure continuing and ready access to primary care, as well

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as to pediatric specialists who can coordinate the care of children with specialized health care needs. The latter is especially important, since children are more vulnerable to delays than are adults. They develop serious complications more rapidly than adults, because they have less physiological reserves and less fully developed organ systems.

In addition, it also is important for managed care systems to reflect in their reimbursement the different needs of children and the different resource demands on the children's hospitals, including care to low income patients, emergency and specialized care, and medical education. For example, children require about 50% more nursing care than do adult patients. And children's hospitals carry a greater burden of graduate medical education, because -- with only about 10% of all pediatric hospital beds in the country -- they account for more than 25% of pediatric residency training.

The risk of pursuing managed care first and foremost for the purposes of cost containment -- particularly given the serious inadequacy of existing public financing and reimbursement for health care for children of low income families -- is that it will discourage rather than improve children's access to the full range of health care services they need. NACHRI believes that managed care must:

- ensure adequate reimbursement for efficiently and economically delivered health care services, with appropriate payment adjustments to meet the needs of providers serving a disproportionate share of low income patients;
- prohibit arbitrary limits -- such as durational inpatient stay limits or dollar caps -- on inpatient hospital care;
- ensure recognition of specialized care management and financial requirements of health care for "children with special health care needs;" and
- ensure the fiscal solvency of managed care entities and the quality of care for which they contract.

Conclusion

As the Select Committee continues to explore the impact of health care reform proposals on children's access to health care, NACHRI would be pleased to be of assistance.

DIFFERENCES IN HEALTH CARE UTILIZATION BETWEEN CHILDREN AND ADULTS

Health Care Utilization	Children	Elderly
Ambulatory visits/ individual/year (a)	5.4/year (under age 5) 2.9/year (ages 5 - 17)	8.3/year (ages 65+)
Hospital admissions/ 100 people/year (b)	5.7/100 children under age 15	>36.8/100
Average length of stay (c)	4.6 days	8.7 days
Number of acute conditions/ individual/year (d)	3.3/year (under age 5) 2.4/year (ages 5 - 17)	1/year (ages 65+)
Annual costs of personal health care/individual/ year (e)	$745/year/ child under age 19	$5,360/year/ individual 65+

(a) National Center for Health Statistics, "Current Estimates From the National health Interview Survey, United States, 1985," Table 1, page 13.

(b) National Center for Health Statistics, "Utilization of Short-Stay Hospitals, United States, 1985," Table B, page 3. (Excludes newborns.)

(c) National Center for Health Statistics, "Utilization of Short-Stay Hospitals, United States, 1985," Table B, Page 3. (Exclude newborns.)

(d) National Center for Health Statistics, "Current Estimates from the National Health Interview Survey, United States, 1985," Table 1, page 13.
3, pages 116-117.\

PREPARED STATEMENT OF THE AMERICAN ACADEMY OF PEDIATRICS, WASHINGTON, DC

The American Academy of Pediatrics is an organization of 43,000 physician members who are dedicated to the health, safety and well-being of infants, children, adolescents and young adults. We thank you for inviting us to address the important issue of children's access to health care.

The Case for Children First:

The Academy believes all United States citizens deserve proper medical care, but we believe that, as we move towards universal health care reform, the first step should be health care coverage for children and pregnant women. Our children simply cannot afford the time it may take to debate and enact a universal health care reform bill. For far too long, children's lack of access to health care has been slighted by our society. As this Committee knows, we cannot afford to ignore this crisis any longer. The time has come for this country to become a nation that makes the health and well-being of its children its highest priority.

The fact is, children, our most vulnerable population, are 29% of the population, but they represent 36% of the uninsured. Approximately 12.5 million children have no health insurance. Millions more children are underinsured. They are without adequate insurance coverage for necessary treatment services and for even the most basic care needed to prevent unnecessary disease and death. Still others are "uninsurable" because of preexisting chronic or recurring conditions. Families with special needs children should not be further burdened with significant concerns about how to finance the critical and often multiple health services needed.

Surprisingly, a large number of uninsured children do not come from stereotypical "poor families". The majority live in two parent families where there is at least one parent who is a full-time employee earning an income above the poverty line. Less than one in four is from a minority household. These families are not covered by either Medicaid or private health insurance; they fall between the cracks of a system that requires them to pay for all health care services out of their own pockets.

Problems with Insurance:

The majority of health insurance coverage in America is provided through employers, but the availability and quality of employer-based insurance, especially for employee dependents, is declining. Economically pressed employers are either dropping dependent health insurance, reducing the benefit packages, and/or requiring employees to pay a higher share of premium for dependent coverage, thereby discouraging dependent coverage. Between 1981 and 1986, the number of employers that fully covered employee's dependents declined from 51% to 35%. Nearly 1/4 of uninsured children have insured parents. In addition, plans that do cover dependents often fail to meet basic health needs of children.

Children's medical care needs and consequently their utilization and costs are very different from adults. Most child health services are provided in an ambulatory setting and are often not covered by health insurance (immunizations, prenatal visits). Private health insurance plans have an array of benefits designed to cover an adult pattern of utilization (inpatient care and high-cost procedures), but they do not address children's needs.

Value of Preventive Care:

Not only are uninsured children unable to receive medical attention when they are sick, but they also fail to receive preventive care. Preventive care, the hallmark of pediatric practice, is poorly covered if at all, despite the economic payback and medical efficacy of childhood immunizations, injury prevention counseling, and screening for anomalies which can prevent or lessen lifetime disability when detected early. This results in unnecessary suffering for the child and his or her family along with higher costs. The Academy believes that preventive care is critical to any proposal designed to provide a healthier future for our children.

Lack of preventive care can lead to dire consequences. Uninsured children tend to experience delays in care leading to more expensive, and less effective treatment with poor outcomes. Uninsured children are less likely to be immunized than children with insurance. In fact, the percentage of fully immunized two-year-olds is decreasing. One in four

American pre-school children is incompletely immunized against diseases including measles, whooping cough, mumps and polio. Outbreaks of these preventable diseases are increasing. Between 1983 and 1990, the incidence of measles increased nearly 1800 percent - despite the fact that this deadly disease is easily prevented by immunization. The goal of the U.S. Public Health Service was to reduce the number of measles cases to 500 by 1990. Instead, the nation averaged 500 cases per week that year, which translated into roughly one death a week among preschool-age children. How can we, as a nation, stand by and not act?

Our children do not have to suffer. Vaccines have been highly effective in preventing infectious diseases. Along with the obvious health benefits, vaccines are cost-effective as well. For every $1 spent on immunizations, we save an estimated $10 in future health care costs. Prenatal care, perhaps the best investment society can make in terms of immediate and long-term savings, is frequently excluded from private insurance. For every $1 spent on quality prenatal care, more than $3 can be saved by reducing the number of low birthweight babies. Ensuring proper health care for our children is crucial to our nation's future. The Carnegie Institute reported that 70 percent of teachers had students whose education was adversely impacted by poor health or nutrition. Our nation's ability to compete in the world market of tomorrow, depends on the type of health care we provide our children today.

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The Case for Pregnant Women:

Health insurance problems affect children even before they are born. One of every four pregnant women is not insured for maternity care, and a comparable proportion do not receive any prenatal care during the first trimester. Lack of counseling about proper nutrition and use of alcohol, tobacco and drugs, can result in low-birthweight babies, prematurity and a high rate of infant mortality. In 1950, the United States had the sixth best infant mortality rate in the world. It has since plummeted to 21st - behind Singapore, Spain and other poorer countries. Our infant mortality rate is now higher than that of any other industrialized nation.

The First Step:

The moral imperative and the value of preventive care and early intervention for children and pregnant women, are strong arguments for starting our march towards universal access with children and pregnant women.

Over the past two years, the American Academy of Pediatrics has focused its efforts on developing a plan entitled "Children First", to provide financial access to health care for children through age 21 and all pregnant women. We are pleased that Congressman Robert Matsui, along with 39 bipartisan cosponsors, has introduced H.R. 3393, "The Children and Pregnant Women's Health Insurance Act of 1991", legislation modeled after the Academy's "Children First"

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legislative proposal. This legislation essentially establishes health care as a right for all children and pregnant women, and it can serve as a model to expand financial access to the health care system for other age groups. Such a plan embraces the principles presented earlier in the hearing by Sarah Brown from the Institute of Medicine.

Conclusion:

As pediatricians, we witness events that the rest of society would choose to ignore -- the consequences of the lack of access to health care intertwined with social and environmental travesties. These include: addicted infants, school failure due to malnutrition, children needlessly maimed by environmental hazards, children suffering long-term sexual abuse and children suffering needlessly from diseases that could have been prevented.

At this time, when the awful state of our children is becoming apparent to all who are willing to look and capable of seeing, when the consequences are frightening to all who can look to the future and understand the implications of the present, we cannot accept rhetoric and token actions, be they well-meaning or self-serving. We must demand pragmatic proposals for meaningful action. Putting our children and pregnant women first under national health care reform is an important step in the right direction.

Prepared Statement of Bob Griss, Senior Health Policy Researcher and Co-chair, Health Task Force Consortium for Citizens with Disabilities, United Cerebral Palsy Associations

May 15, 1992

House Select Committee on
Children, Youth & Families
385 Ford House Office Building
Washington, D.C. 20515-6401

Enclosed is the CCD Health Task Force testimony on the Principles for Health Care Reform from a Disability Perspective for the hearing record of the House Select Committee on Children, Youth & Families.

I hope we have an opportunity to work more closely with your Committee on future hearings and educational strategies around the need for comprehensive health care benefits. Ironically, these are not included in small group insurance reform proposals, or in the minimum benefit package of "Play or Pay" proposals, or even in the existing Medicare benefit package.

We believe that the health care crisis cannot be solved by extending acute-care oriented health insurance to all persons when a majority of Americans have chronic health conditions. Unless these issues of comprehensive health benefits are better understood by Congress and the American people, the growing pressure for cost containment will undermine access to the health care benefits that persons with disabilities or chronic illness are likely to need.

Looking forward to working with you on these critical issues, I remain,

Sincerely,

Bob Griss

Bob Griss

Senior Health
Policy Researcher
and
Co-chair, Health Task Force
Consortium for Citizens
with Disabilities

Consortium for
Citizens with
Disabilities

STATEMENT OF THE
CONSORTIUM FOR CITIZENS WITH DISABILITIES
HEALTH TASK FORCE
to the
SELECT COMMITTEE ON CHILDREN, YOUTH, AND FAMILIES
of the
U.S. House of Representatives
on the subject of

"HEALTH CARE REFORM: HOW DO WOMEN, CHILDREN, AND TEENS FARE?"

May 5, 1992

ON BEHALF OF:

AIDS Action Council
Alliance of Genetic Support Groups
American Academy of Physical Medicine and Rehabilitation
American Association for Counseling and Development
American Association of University Affiliated Programs
American Association on Mental Retardation
American Civil Liberties Union
American Congress of Rehabilitation Medicine
American Foundation for the Blind
American Occupational Therapy Association
American Physical Therapy Association
American Speech-Language-Hearing Association
Association for Retarded Citizens of the United States
Epilepsy Foundation of America
Immune Deficiency Foundation
International Association of Psychosocial Rehabilitation Services
Learning Disabilities Association
National Alliance for the Mentally Ill
National Association of Protection and Advocacy Systems
National Association of Private Residential Resources
National Association of Rehabilitation Facilities
National Association of Developmental Disabilities Councils
National Association of State Mental Retardation Program Directors
National Council on Independent Living
National Easter Seal Society
National Head Injury Foundation
National Mental Health Association
National Multiple Sclerosis Society
National Organization for Rare Disorders
National Parent Network on Disabilities
National Recreation and Parks Association
National Rehabilitation Association
National Transplant Support Network
Spina Bifida Association of America
The Association for Persons with Severe Disabilities
United Cerebral Palsy Associations, Inc.
World Institute on Disability

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PRINCIPLES FOR HEALTH CARE REFORM FROM A DISABILITY PERSPECTIVE FROM THE HEALTH TASK FORCE OF THE CONSORTIUM FOR CITIZENS WITH DISABILITIES

INTRODUCTION

Ms. Chairwoman and Members of the Committee. The organizations represented in CCD's Health Task Force appreciate the opportunity to express our priorities for health care reform from a disability perspective. The time is ripe to sharpen the debate for national health care reform. We commend the Ways and Means Committee for holding this series of hearings to focus this debate on one of the most important civil rights issues of the 1990's.

The Consortium for Citizens with Disabilities is a working coalition comprised of over 70 consumer, service provider, and professional organizations which advocate on behalf of persons with disabilities and their families. This statement is presented on behalf of 37 national organizations who comprise the overwhelming majority of CCD Health Task Force members. The more than 43 million Americans with disabilities include individuals with physical or mental impairments, conditions, disorders, severe acute or chronic illness which limit or impede their ability to function. Such disabilities may occur as a result of disease, injury, sudden trauma, aging, or congenital anomaly. One of the reasons for the passage last year of the historic Americans with Disabilities Act was to finally recognize not only the existence and importance of these millions of Americans with disabilities, but also to ensure their individual civil rights.

When one considers the numbers and range of individuals covered by the definition of disability, it is no wonder that the issue of access to appropriate, adequate, and affordable health care and related support systems is of such critical importance to the CCD. In fact, while 43 million is the official number cited for persons with disabilities, the CCD believes that, in actuality, this number is an under-estimation. Therefore, it is also no wonder that any discussion of reform of the nation's health care system must include not only the generic consumer perspective but also the unique perspective of consumers with disabilities. It is the belief of the CCD that addressing the disability perspective in the current health care reform debate will ultimately benefit all Americans.

In considering the issue of health from the disability perspective, it is essential to re-focus our conception of what being "healthy" really is. For so many people with disabilities health is determined by functional capacity. It is the ability to maintain or increase this functional capacity that is often the measure of the person with disabilities opportunity to live an independent life and participate as fully as possible in the life of the community. True realization of the rights now guaranteed by the ADA and other important pieces of civil rights legislation, unfortunately, will continue to be limited as long as people with disabilities do not have access to a seamless array of life-long health, personal, and support services.

The CCD has determined that any effort to reform the nation's health care system must be built on five basic principles: non-discrimination, comprehensiveness, appropriateness, equity, and efficiency. Only in this manner can we ensure that national health care reform efforts take into consideration the needs of Americans with disabilities.

PRINCIPLES

The CCD believes that any ultimate solution to the health care crisis must be based on the principle of non-discrimination ensuring that people with disabilities of all ages and their families have the opportunity to fully participate. The CCD would define a successful health care system as one that offers a comprehensive array of health, rehabilitation, personal, and support services, as well as a system that ensures that these services are appropriate in that they are provided on the basis of each individual's need, personal choice, and situation. In addition, any truly effective solution must be equitable ensuring that no group of individuals bears a disproportionate burden. Finally, the CCD asserts that an effective and accessible health care system must be efficient ensuring that system resources are utilized to meet health care needs. The CCD strongly supports the right to health care for all persons regardless of income or health status.

Non-Discrimination: People with disabilities of all ages and their families must be able to fully participate in the nation's health care system.

People with disabilities are often discriminated against in the health insurance marketplace because they are presumed to be high health care users. In fact, most people with disabilities are not sick. Nevertheless, private insurers use medical underwriting practices which are designed to ensure that high users of health care are charged higher premiums, subjected to preexisting condition exclusions, or rejected totally as an "unacceptable risk". Discrimination occurs when a sizeable proportion of persons with disabilities who are actually low users of health care are denied insurance or subjected to preexisting condition exclusions. Discrimination also occurs when high users of health care are denied adequate coverage because they cannot afford the premiums or are subjected to limitations on covered services. From a disability perspective, the very practice of experience-rating which ensures that premiums are set on the basis of previous utilization, is a form of unfair discrimination against high users.

Access to health care for individuals with disabilities cannot be considered in a vacuum. Historically, discrimination on the basis of disability has limited opportunities in employment, education, housing, travel, and other aspects of daily life. Now, with rights guaranteed in so many of these areas by the passage of the Americans with Disabilities Act and other important civil rights legislation, there is a growing realization in the disability community that access to health care is a major barrier that threatens to interfere with the attainment of these rights. The CCD believes that the present inability of a substantial proportion of people with disabilities to participate in the nation's health care system at a level which meets their needs is a direct reflection of the continued misperception of both the skills and needs of people with disabilities. Non-discrimination requires that the health care financing system:

- prohibits pre-existing condition exclusions;
- prohibits rating practices that discriminate against higher users of health care;
- ensures that all persons, regardless of income or health status, have access to the all needed health related services;
- provides access without regard to age, race, place of residence, or the characteristics of persons with whom one maintains family relationships;
- ensures continuity and portability of coverage.

Comprehensiveness: People with disabilities and their families must have access to a health care system that ensures a comprehensive array of health, rehabilitation, personal, and support services across all service categories and sites of service delivery.

The CCD asserts that an effective and comprehensive health care system, one that is responsive to the needs of people with disabilities, would provide a seamless array of life-long health related services. Comprehensiveness implies the broadest set of services that assist individuals with disabilities and their families to achieve and sustain optimum physical and mental function. The terms "health, rehabilitation, personal, and support services", used by the CCD, refers to a universe of services delivered by a range of practitioners in a variety of sites and illustrates the necessary breadth of a health care delivery system that is truly accessible to people with disabilities. Over the course of a lifetime, all people commonly require a broad array of health, rehabilitation, personal, and support services. However, access to the entire array of these services must be ensured for people with disabilities. Often it is the availability of these services that can determine their ability to live independent lives and fully participate in the community. Moreover, adequate access can prevent exacerbation of a small health problem from developing into a larger more costly health problem. People with disabilities would most benefit from a health care system that includes access to:

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- preventive services, including services to prevent the worsening of a disability
- health promotion/education services
- diagnostic services
- inpatient and outpatient physician services
- hospital inpatient and outpatient care
- long term care in medical facilities
- long and short term home and community-based services
- prescription drugs, biologicals, and medical foods
- mental health and counseling services
- habilitation services
- rehabilitation services, including audiology, occupational therapy, physical therapy, respiratory therapy, speech-language pathology services, cognitive, vision, and behavioral therapies, and therapeutic recreation
- personal assistance services and independent living services
- durable medical equipment and other assistive devices, equipment, and related services

Appropriateness: People with disabilities and their families must be assured that comprehensive health, rehabilitation, personal, and support services are provided on the basis of individual need, preference, and choice.

Particular attention must be placed on the appropriateness of available services. It is of critical importance to the disability community that full involvement of the "consumer" is assured in all decisions affecting the selection of service, service provider, service timing, and service setting. CCD is concerned that certain forms of managed care create an incentive for under-serving persons with disabilities and often utilize gate-keepers who are not knowledgeable about the special health care needs of persons with disabilities.

The issue of consumer choice and participation has a particular importance for persons with disabilities. While the present acute-care oriented health care system has a tendency to relegate all "consumers" to a dependent status embodied in the "sick role", this indignity is particularly disempowering to persons with disabilities when their chronic health conditions are permanent. That is why the health related services for persons with disabilities must be delivered in a way that minimizes interference with normal activities, and that health care financing policies which govern access to health care for persons with chronic conditions must be sensitive to issues of locus and control.

It is essential that decisions about health care services reflect personal preference and maximum benefit to the individual rather than provider and service setting availability, cost-containment goals, or coverage limits. CCD asserts that meaningful access to health care involves the right of the individual consumer to participate in the decision-making process regarding the provision of needed services and to be educated so appropriate self-care is possible.

In addition, CCD strongly believes that persons with disabilities must be involved in policy decisions that will guide the nation's health care system. An appropriate health care system is one which:

- includes consumer participation;
- ensures consumer choice in relation to services and provider;
- ensures a range of service settings through an integrated delivery system;
- ensures appropriate amount, scope, and duration of services;
- ensures the availability of trained personnel.

Equity: People with disabilities and their families must be ensured equitable participation in the nation's health care system and not burdened with disproportionate costs.

The CCD asserts that equal access to health services will not be readily achievable unless payment for health, rehabilitation, personal, and support services is equitably distributed so that no individual or public or private sector interest is burdened with a disproportionate share of the cost. Because of cost issues, too often people with disabilities and their families have been required to make unfortunate choices between needed health services in appropriate settings and what they can afford. These types of choices obviously do not reflect the principles of non-discrimination, comprehensiveness, and appropriateness of services. Health care reform must ensure that people have access to services based on health care need and not on their employment status or income level. As a group, people with disabilities have lower incomes than the general population and many adults with disabilities and families with members with disabilities devote a disproportionate share of their income to health care and disability related services. An equitable health care system would be one which:

- limits out of pocket expenses and cost sharing requirements for participants;
- provides access to services based on health care need and not on income level or employment status;
- ensures adequate reimbursement for service providers;

Efficiency: People with disabilities and their families must have access to a health care system that provides a maximum of

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appropriate effective quality services with a minimum of administrative waste.

The CCD is concerned that the current fragmentary system has failed to achieve effective cost controls, or a rational allocation of health resources, and contributes to substantial administrative waste. It is estimated that more than 20 percent of health care expenditures are attributed to administrative costs as 1500 private health insurers require different forms of provider documentation to trace every claim for reimbursement to the utilization by a specific individual with his or her own health insurance plan. In addition, the fragmentary system has contributed to the growth of excess capacity in the health care delivery system, inviting cost shifting, and undermining efforts to achieve effective cost controls. This has reinforced pressures for arbitrary cost containment by limiting coverage in ways that often adversely affect persons with disabilities.

Moreover, health care financing policy has not evolved much beyond acute care, failing to respond to the growing need for preventive care and for chronic health care management which could significantly reduce the growth of preventable diseases.

An efficient health care system is one that:

- reduces administrative complexity and minimizes administrative costs;
- allocates resources in a more balanced way between preventive services, acute care, rehabilitation, and chronic care management;
- ensures the delivery of effective services;
- maintains effective cost controls so that all people can get the health care services which they need.

Based on these "principles" from a disability perspective, CCD is reviewing various health bills before the House of Representatives, and will submit a formal statement of our assessment of these bills as soon as we complete our analysis.

CONCLUSION

The disability community needs to be a major player in reexamining health care financing policy. People with disabilities are highly vulnerable to the limitations of both public and private systems as they are squeezed between a private system which is designed to charge according to an assessment of risk and a public system which subsidizes health care according to age, poverty status, family structure, and an inability to work.

Private health insurance was developed and has remained a method

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for spreading risk of incurring excessive costs primarily for hospital and physician services. For individuals with disabilities, access to health care has been severely restricted because of preexisting conditions and the mistaken assumption that most people with disabilities need more hospital and physician care than the population as a whole. Health care reform needs to eliminate this restriction and assure access to needed hospital and physician services. Equally as important, the tradition of limiting covered services to hospital and physician services must be changed. Rehabilitation services, personal and support services, mental health services, and assistive technology must be recognized as essential components of health care.

Perhaps our greatest contribution will be in clarifying the principles which should guide our health care system. These include: (1) expanding the definition of "health" to include prevention services, rehabilitation therapies, assistive technology, and on-going health-related maintenance services; (2) distributing all health related expenses equitably throughout the population; and (3) restructuring our health care delivery system to more effectively support consumer-directed chronic care management.

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For more information, please contact any of the CCD Health Task Force Co-chairs:

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PREPARED STATEMENT OF STEVE A. FREEDMAN, PH.D., F.A.A.P. (HON.) EXECUTIVE DIRECTOR, INSTITUTE FOR CHILD HEALTH POLICY, ASSOCIATE PROFESSOR OF PEDIATRICS AND HEALTH SERVICES ADMINISTRATION, UNIVERSITY OF FLORIDA, GAINESVILLE, FL

Distinguished Chairman, Members of the Committee, I am Steve Freedman. I direct the Institute for Child Health Policy of the State University System of Florida and I also have the privilege of directing the National Center for Policy Coordination in Maternal and Child Health which is supported by a grant from the Maternal and Child Health Bureau of the U.S. Public Health Service (MCHB).

On March 31, 1988, an article was published in the *New England Journal of Medicine,* that outlined the School Enrollment-based Health Insurance concept. Subsequent to the publication of that article, the Robert Wood Johnson Foundation provided a planning grant to the Institute to develop a demonstration of the concept. The Foundation's interest stemmed from their broad national concern for finding alternative mechanisms to finance access to health care for the uninsured. In addition, the Maternal and Child Health Bureau of the U.S. Public Health Service has provided funds to the National Center to determine the feasibility of the proposed program of School Enrollment-based Health Insurance. MCHB was motivated to provide that support, in part by its commitment under Title V to assuring family centered, community-based comprehensive care.

Context of the Proposal

The proposal for School Enrollment-based Health Insurance evolved out of our understanding of the current financing and access issues related to adequate health care in the United States. Because I am aware that this Committee and its professional staff are fully cognizant of the statistics surrounding the issue of the uninsured, I will not take up your time reiterating those data.

I would like to begin with two fundamental principles. The first is that all individuals in this country participate in the health care risk pool. The second is that there is no such thing as uncompensated care. Let me explain. Sometime during their lifetime, virtually every individual in this country will seek and secure access to health care. In financing terms that access is called "risk". All those who secure access make up what is termed the "risk pool". However, not all individuals participate in financing the cost of that risk pool. Hence, the financing of that risk is disproportionately distributed to and subsidized by policy-holders and taxpayers through premium increases and tax increases. That brings me to my second point, i.e., there is no such thing as uncompensated care. Compensation is received by providers for all health care events. However, that compensation is not always paid directly by the individual receiving the care or from a public or private insurance program intended to support the care for that individual. Sometimes the compensation is paid indirectly through increased premium rates for those who are insured and increased taxes for those who must support publicly financed programs. Thus, while there may not be any uncompensated care, there is an overwhelming amount of inappropriately financed care. For example, last year in Florida, $600 million in hospital care was described as uncompensated. However, I can assure you that, in this and subsequent years, this care will be inappropriately financed by increases in per diem rates charged to public and private insurers. Consequently, one of the underlying principles behind the School Enrollment-based Health Insurance Program is that we must find ways to encourage all individuals and families to assume some financial responsibility for the cost of their own health care. It is important to get those who are capable, but now pay nothing, to pay something, because the cost of their care is paid for by the rest of us. The $64 billion question is - how?

Like most programs on the current public agenda attempting to deal with the problems of the uninsured, School Enrollment-based Health Insurance is not intended to be a universal solution. However, our approach does have broad applicability. From our understanding of the existing data, we have concluded that nearly two-thirds of the uninsured are members of the immediate family of an individual enrolled in school. You already know that the uninsured tend to be young individuals who are employed in circumstances that, as a practical matter, don't offer affordable health insurance. You also know that the largest single uninsured segment of our society is children. Logically, these children are linked to uninsured employees in a majority of cases. As a consequence, the School Enrollment-based Health Insurance idea is based upon school enrollment since it is the common bond that links many of the uninsured together within families.

I want to re-emphasize that the uninsured typically are employed but have a limited economic capacity to afford what has become a prohibitively expensive product, health insurance. The fact is that there is a direct statistical relationship between income and insurance coverage. Another germane fact is that most uninsured individuals and families have some resources with which to participate in the cost pool. However, they can neither afford the full premium for a health insurance policy nor the bill for a single day in most major hospitals.

I cannot help but note the rapidly waning availability of commercial group health insurance for small businesses. This is due in large part to the high cost of insuring groups of small size for risk-spreading. Additionally, the federal ERISA legislation has had an impact on the cost of health insurance. The exemption of ERISA qualified plans from state mandates and state taxes leaves employers, public and commercial insurers holding the bag. Not only must these groups comply with state public policies, but they are also left with the responsibility of the unpaid costs that are shifted as a result of the uncovered, but used, health care services of ERISA plan employees. In fact, ERISA has caused many commercial insurers to move rapidly away from insuring health risk and toward the administration of self-insurance plans. Consequently, at this time, commercial group health insurance is becoming available only to large groups. This fact brings me back to school systems as grouping mechanisms that can provide the kinds of large groups that are still attractive to insuring organizations.

Concept of School Enrollment-based Health Insurance

Underlying the concept of School Enrollment-based Health Insurance, is the idea of a private/public partnership similar to the private/private partnership in employment-based insurance. In traditional group health insurance, the employer subsidizes premiums and is the policy-holder; the employees are the certificate-holders either for themselves alone or for themselves and their dependents. Under the School Enrollment-based Family Health Insurance proposal, the school system or other public entity subsidizes premiums and is the policy-holder; the students are the certificate-holders either for themselves alone or for themselves and their parents, siblings and their own children.

This will not be a new role for school systems. School systems are currently policy-holders for teachers and other employees and administer health insurance plans. While implementation of School Enrollment-based Health Insurance would be an expansion of that administrative activity it is not a wholly new responsibility for school systems.

Given what I have already said about the economic characteristics of the uninsured, it is clear that in order to encourage their participation in payment of premiums, some sliding scale subsidy must be made available. Once again, school systems have substantial administrative experience with sliding scale subsidy programs through their administration of the school lunch program.

Indeed, school systems have another existing function that would be of inestimable value in adequately administering a proper family health insurance program. That significant asset is their capacity for health education. Private businesses and industries have only recently begun internal health education programs to assist employees to understand self-help health measures and prudent utilization of health care resources. The school systems, on the other hand, have been in that business for some considerable time and could integrate that function with a comprehensive health insurance program.

As an aside, Florida's Commissioner of Education, Betty Castor, noted that if a family is dependent for health insurance on the active school enrollment of a child, it is likely that this may have a positive impact on the family's efforts to avoid having Johnny dropout of school. Additionally, Florida's Secretary of Health and Rehabilitative Services, Robert Williams, has been most supportive because he recognizes that, as families rise economically from the public assistance rolls and lose Medicaid coverage, this program provides an opportunity for continuing health care access. Both of these public officials have committed themselves to support a full demonstration of the proposal.

A School Enrollment-based Health Insurance Demonstration in Florida

Having described the context for School Enrollment-based Family Health Insurance and the concept of the program, let me share with you one effort at demonstrating this concept in Florida.

In reviewing the legal basis for such a program, we rapidly discovered that existing group health statutes adopt the traditional view of the employer as the principal grouping mechanism. Accordingly, most group health insurance laws are written to permit coverage of the employee as the certificate-holder and, through the employee, coverage of dependents. Clearly, parents, siblings, and the children of a student in school are not dependents of that student. Recognizing that, the Institute worked with State Representative Lois Frankel and State Senator Jeanne Malchon to have legislation introduced to modify Florida's insurance code to permit school systems to be policy-holders, students to be certificate-holders and parents, siblings and children of students to be insured under the student's certificate. The Florida Legislature passed and the Governor signed into law a law permitting that new grouping mechanism. It should be noted that there was bi-partisan support for the measure and the measure passed unanimously in both Houses of the Florida Legislature.

In planning for the design of this program, the Institute brought together a distinguished panel of advisors representing insurers, benefits managers, insurance regulators and leaders from human services and education to critique the evolving concept. Through those deliberations, several themes came to the fore. First, limiting benefits does not control costs. Needed services will be utilized even if no insurance benefits exists and the cost of those services will be shifted inappropriately to existing payment mechanisms. As a consequence, we have planned a comprehensive benefit package similar to the benefits outlined by the American Academy of Pediatrics and those already provided for under the Medicaid Early and Periodic Screening, Diagnosis, and Treatment Program. A second theme was that managing utilization can control costs. As a consequence, our planning includes a professional triage and case management function to assure appropriate and timely utilization.

The third theme to evolve was that enrollment should be both open to all uninsured children and mandatory for that group. Under that formulation, eligibility is only an issue of eligibility for subsidy. Uninsured children and their families would have access to the program on a subsidized, sliding scale basis. Naturally, as with employment-based insurance, the certificate-holder (student) may elect to be insured alone or may optionally insure uninsured parents, siblings and children. As one of our advisors put it, "If immunizations are mandatory for school attendance, why shouldn't health insurance be? If everyone is required to participate within their means and subsidized to assure affordability why shouldn't the program be mandatory?" In many private businesses, participation in the health insurance benefit is mandatory. For

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example, my wife is an officer with a large banking group that offers a cafeteria plan, including health insurance with a variety of options. However, the corporation requires participation in the minimum health insurance plan irrespective of any other fringe benefit selected or any other health insurance coverage that exists within the family.

At this point in the demonstration's history, the 1990 Florida Legislature, at the urging of the state commissioners of insurance and education, passed the Healthy Kids Corporation Act which became law July 1, 1990. In the summer of 1990, a joint proposal was prepared and forwarded to the Health Care Financing Administration (HCFA) by the Institute, the Florida Medicaid Program and the Healthy Kids Corporation. The proposal sought financial support for a School Enrollment-based Health Insurance demonstration project to be administered by the Healthy Kids Corporation. Subsequently, HCFA selected the joint proposal and a four-year cooperative agreement was established. The support from HCFA, in combination with state and private contributions, has provided resources to subsidize the premiums for children from low-income families, as well as program development and administrative costs.

The health care provider was selected as a result of a public request for proposals to serve in Volusia County, Florida. Florida Health Care Plan, a Health Maintenance Organization, already operating in Volusia County, was selected as to provide the physicain network, health services, and case management. Barnett Technologies, Incorporated (BTI) performs claims processing and monthly premium collection. The Institute will provide an evaluation of the demonstration's effectiveness. Enrollment in the insurance program began in Volusia County, Florida in February, 1992. Applications have greatly exceeded expectations with over 6,000 children seeking enrollment in the program thus far, and 4,000 of the applicants are currently active enrollees.

The Institute and the Healthy Kids Corporation have reviewed a range of options for continued financing of the program and is now exploring the following concepts. First and foremost is the requirement for family participation in the cost, both directly out-of-pocket and, where appropriate, subsidized by an employer. Small employers with limited resources who offer no health insurance because of the exorbitant cost to small groups, may find participation in this plan economically attractive and feasible. Indeed, small businesses and families in better economic circumstances could be permitted to participate at full cost with no subsidy.

For most participants, public funding would be needed at two levels: premium subsidy and stop-loss protection. The reality is that states already subsidize health care for the uninsured through cost shifting into Medicaid and other health programs supported by state revenues. Some of the funds currently misdirected in that way might be redirected into premium subsidies, an alternative which could serve to lower the burden of financing shifted costs.

An example of creative reprogramming of funds would be to use state Title V Program for Children with Special Health Care Needs as a stop-loss mechanism for children insured under this program. The stop-loss would be invoked for any participating child reaching an annual expenditure threshold, e.g., $25,000. Because it is likely that any child with $25,000 of health expenses has special health care needs, it would be appropriate for the Title V program to participate in this way. The trade-off would be that the first $25,000 for that child's care would come from the School Enrollment-based Family Health Insurance Program and not the state's Title V Program, as it does now. Of great importance is that a stop-loss provision would substantially enhance the attractiveness of the program to private sector insurers.

Because of recent improvements in the Medicaid program we are also exploring methods for articulating that program with School Enrollment-based Health Insurance, both in benefit structure and premium subsidy. The state has a compelling interest to assure that people make a successful transition out of public assistance. One significant factor in that transition is the assurance of continuing health care coverage. We would look to the Medicaid program to subsidize premium during that transition since it would be more cost-effective to pay a premium subsidy than to continue to pay the full cost for all care.

This program is not expected to be budget neutral for the state. Premium subsidies would require some level of enhanced state funding. However, policy makers at both the state and federal levels have long recognized that the assurance of access to adequate health care for all people requires public support; that healthy citizens are more likely to be taxpayers and unhealthy citizens are more likely to be tax consumers.

In the final analysis, the total cost for the care of those insured through School Enrollment-based Health Insurance could be substantially reduced. I make this assertion based on data which the Institute collected in a 1988 state-wide health insurance survey of Florida families with children. One of our findings was that uninsured children had hospital lengths of stay nearly twice that of insured children, a very expensive difference. In fact, when we closely examined the results of that survey, we found that for children who were hospitalized, only 19% of the insured had lengths of stay greater than 5 days, while 43% of the uninsured had lengths of stay greater than 5 days. Thus, it would appear that the provision of health insurance, and the access that comes with it, has the potential to reduce overall expenditures for care.

I will close by expressing my appreciation for the privilege to provide this information to you and to personally thank you for your sensitivity to and advocacy for improving the health of our nation's children.

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SOUNDING BOARD

COVERAGE OF THE UNINSURED AND UNDERINSURED

A Proposal for School Enrollment–Based Family Health Insurance

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COVERAGE OF THE UNINSURED AND UNDERINSURED

A Proposal for School Enrollment–Based Family Health Insurance

TRADITIONALLY, Americans have obtained individual and family health insurance coverage in one of three ways. Some have been covered by public programs (Medicaid for the very poor, Medicare for the elderly), and some have paid directly for policies, but by far the largest number of people have obtained health coverage in the form of group insurance provided through their employers. Insurance programs for members of large groups have had the lowest prices. In most cases, however, low prices have not been extended to small employee groups or to individuals. This aspect of health insurance structure has had adverse financial effects on industry, government, and health care providers and has compromised access to health care for many nearly poor, low- and moderate-income Americans who are not members of sizable groups.

In recent years, a large and growing percentage of the population has had inadequate health insurance coverage or none at all. A number of factors have contributed to this problem. The American economy is changing from being a system dominated by industry to one dominated by service, with a commensurate rise in the number of small businesses and the use of part-time labor. With respect to health insurance coverage, there is an inverse relation between group size and premium level,[1] because large groups provide the opportunity to reduce administrative expenses and distribute risk more widely. As a consequence, small businesses have found it difficult to obtain the favorable group rates enjoyed by larger enterprises, and many workers, particularly those working for a minimum wage or part time, receive no health insurance benefits at all. Among firms with fewer than 25 employees, up to 60 percent offer no health insurance to their workers.[2] When the employer elects to make available a health insurance program without subsidy, many employees may find the premium unaffordable. Even when employers provide individual health insurance for their workers at no cost, the employee may be unable to bear the high cost of supplemental family coverage. And for people whose employers do not provide insurance, the premiums associated with individual policies are often out of reach. Even so, 7 million of the 24 million workers who lack access to group health insurance buy the more expensive private coverage.[3]

Other aspects of the nation's changing economic structure have compounded the problem of access to health insurance. First, the number of low-income and poor Americans has grown. Between 1978 and 1983, the number of people living below the federal poverty level increased by approximately 50 percent.[4] Second, people who must pay for their own health insurance have found the costs increasingly high. Premiums rose almost 40 percent in 1981, and another 30 percent in 1982.[5] Finally, states have imposed more stringent eligibility requirements for Medicaid, reducing the percentage of persons who are covered by that program. Between 1975 and 1986, the proportion of the population below the poverty level that was covered by Medicaid declined by one third.[6] In consequence, the population of the uninsured and underinsured has grown, and the gap between them and persons adequately covered under public and private programs has widened.[7,8] In 1982, Medicaid reached less than half the people under the federal poverty level in 36 states, and in 22 of those states, it reached less than a third.[9]

The economic and social consequences of poor access to health insurance are considerable. People unable to qualify for Medicaid or to afford insurance often go without care until their health deteriorates, and as a result, the care they need is more costly.[10] When charges for these services remain unpaid, providers pass them along as a "sick tax" to public and private payers. This cost shifting has become a major problem for taxpayers, as well as for other payers and providers of health care.

WHO ARE THE INADEQUATELY INSURED?

Here are some statistics relating to Americans with inadequate coverage. First, as many as 65 million Americans, more than 30 percent of the population under 65, have inadequate health insurance protection against large medical bills.[11] Of these, about 35 million, 17.5 percent of the population under 65, are without private or public health insurance coverage at least part of the year.[12,13] Up to 30 million more are underinsured for any serious illness.[2,11]

Second, adequate insurance coverage is strongly related to, but not solely dependent on, income level. One third of the uninsured population have incomes

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above 200 percent of the poverty level, whereas 35 to 40 percent are below the poverty line.[2]

Third, most uninsured adults work. In 1986, 17 million workers, representing about one sixth of the U.S. labor force, were uninsured.[3] More than two thirds of those who have no health insurance coverage live in homes where the head of the household works full time and year round.[11]

Fourth, the number of uninsured Americans is rapidly increasing. The uninsured population rose one third between 1977 and 1984, from approximately 26 million to 35 million.[13]

Furthermore, because employers typically cover workers rather than families, children as a group are disproportionately uninsured. Nearly one American child in five has no coverage, and one third of the uninsured (12 million) are children.[13-15] The chance of being uninsured is 37 percent higher for a child than for an adult. More than a third of all uninsured children (4.1 million) live with a parent or guardian who is insured.[11]

In addition, a lack of insurance coverage translates directly to a lack of health care. Uninsured persons use medical care less often than do insured people, and they are more likely than the insured to be in poorer health.[16,17] In addition, uninsured Americans spend one-third more days per year in bed because of illness than do the insured.[18]

Finally, lack of insurance coverage constitutes a serious financial burden for insurers, providers, and taxpayers. Health insurers, providers, and taxpayers absorb the enormous costs incurred by people who need care but who have neither insurance nor the personal resources to pay. For example, a study of Florida hospital charges in 1985 and 1986 revealed that 72 percent of an estimated $283 million in unresolved hospital care bills was generated by patients under 65 with no health insurance coverage. An additional 16 percent of the unresolved amount was attributable to patients under 65 with inadequate coverage.[19,20]

Plans under Consideration

Policy makers and health planners have become increasingly sensitive to the plight of the uninsured and the immense costs of catastrophic health conditions. In recent years, a number of state and federal programs have been proposed or implemented that seek to ensure access to health insurance for more Americans.[2,12,21-24]

It is questionable whether the plans proposed to date — e.g., those requiring all small businesses to carry insurance for their employees,[23,25] the establishment of state-sponsored high-risk pools,[26] multiple-employer trust funds,[12] or tax-exempt bonding mechanisms[27] — will address the health insurance crisis in a meaningful way. At best, most of these proposals focus on subsets of the problem. It is important to recognize that the inadequately insured population comprises many discrete subgroups with a variety of constraints on access.[28]

There is no panacea to this multidimensional problem, but alternative strategies can be mounted that redefine groups so as to extend coverage to large segments of the uninsured or underinsured populations. One such alternative strategy is described here.

An Alternative: Family Health Insurance Based on School Enrollment

Most American children attend public schools. Approximately 23 million, or two thirds, of the uninsured are children of school age and their young parents.[13,29] To enhance access to health care for children and their family members, state school systems could be used as a grouping mechanism for negotiating comprehensive group health insurance policies. Coverage could be offered to all families with children enrolled in public school. Policies could be designed to accommodate either the individual child or the entire family. Such flexibility would be ideally suited to the needs of parents who receive individual coverage as a fringe benefit of employment but who must pay a relatively large premium for supplemental family coverage. This arrangement is identical to current employment-based insurance structures, except that schoolchildren become the "employees," qualifying both themselves and their family members for coverage. A health insurance program based on school enrollment could be structured to target three groups: the uninsured, the underinsured, and those for whom the program would represent an economically competitive choice. Though the benefit package would be the same for all participants, the enticement for each group might be different. A reasonably priced comprehensive health insurance program would afford access to coverage for the uninsured, better coverage for the underinsured, and a better buy for the economically secure. Indeed, for families in which the wage earner already receives employment-based coverage, the option of coverage for the child only through school-based insurance might be a low-cost alternative to the purchase of employment-based coverage for the family.

In examining this proposal, a number of issues must be considered, but two — adverse selection and cost — are of particular importance. Adverse selection refers to the possibility that the resulting group would be characterized by lower health status and hence by potentially higher rates of insurance use. There is no empirical evidence for this argument; on the contrary, some characteristics of a school enrollment–based group suggest favorable selection. For rating purposes, we assume that the group will be defined on a statewide basis. In addition to being large, the group would be disproportionately composed of persons between the ages of 5 and 50 — those with the lowest rates of insurance use and health care expenditure in the nation.[30,31] The group would not include the population eligible for Medicaid, which is assumed to be characterized by negative health status due to extreme poverty. Nor would the proposed group include many participants from the older, pre-Medicare population, because such persons are unlikely to have school-aged children. Finally, insurers concerned about the high rate of poor and nearly poor clients among the uninsured should be reassured by the potential for heavy participation from the nonpoor — the underinsured and those who would avail themselves of the buying power of a group so large.

The cost issue is also of central importance. Clearly, a program to provide coverage for an uninsured population cannot be created without cost. However, this proposal suggests an initiative that will enhance private group insurance coverage. That is, given the evidence that large group size can affect the cost of health insurance positively, we assume that premiums could be established at a level that would make this an attractive business opportunity for private insurance carriers. Indeed, substantial evidence affirms that insurers already find school enrollment–based groups actuarially attractive. Some insurers already market gap-filling hospitalization and accident coverage to public school children and standard health coverage to college students.

Despite the potential viability of the proposal, premiums are still likely to be beyond the reach of some lower-income families. To ensure the affordability of basic, adequate coverage for all program participants, states could subsidize insurance premiums on a sliding scale based on income, just as they currently subsidize school lunch programs. In addition, the experience that most school districts already have in administering health insurance programs for their faculty members and other employees would equip the school systems to administer the proposed plan skillfully.

Given the potential size of a statewide group comprising all public school children and their families, it should be possible to design an insurance benefit and premium package that could adequately address some of the difficulties inherent in employment-based health insurance programs. For example, the small employer could easily "buy in" to a school-based program for employees with school-aged children. Furthermore, moving the insurance company's point of contact from the employer to the school system enhances the "portability" of coverage for the family. Under the traditional plan, employees wishing to change jobs often risk disrupting a family member's coverage in the process, especially when the family member has a preexisting illness.

Benefit packages could be designed to meet the comprehensive health needs of schoolchildren. Appropriate benefits for child health and developmental supervision, currently mandated in only one state (Florida), could be part of the design. Special health services provided by the school for physically and educationally handicapped children and not now covered by private health insurance — e.g., physical, occupational, and speech therapies — could be included. Because many school systems already provide a range of health-related services for handicapped children, insurance benefit packages that recognized those services might offset some of the related costs and the associated tax burden.

The social benefits of such a program might be considerable. With access to better health care, including primary and preventive services, children and their parents might become more resistant to illness and lose fewer days from school or work. Children with a more positive health status tend to perform better in school. A less obvious but equally important point is that families that depended on their child's enrollment to maintain their own health insurance would not readily permit the child to drop out of school and risk losing the "fringe benefit" of family health insurance. As with insurance in the workplace, access to health benefits would provide an incentive for staying in school, and thus might contribute to a valuable framework of family responsibility. Finally, with a larger proportion of the population insured for health care, the burden of the sick tax would be reduced dramatically.

The concept of family health insurance based on school enrollment constitutes a private-sector effort to solve an important problem of public policy. Benefit packages and actuarial assessments developed under state supervision would form the basis for bids from private carriers. The mainstream community of health care providers would supply health care. The cost of subsidies, where necessary, could be offset by a reduction in the requirement for publicly supported programs of direct health care delivery. For example, county public health departments often receive state funding to operate public clinics, which are constituted to provide alternative access to health care for the uninsured. To the extent that the proposed program diminished the uninsured population, funding for such clinics could be diverted to premium subsidies. Furthermore, this type of insurance programming might receive the support of industry, which has expressed dismay at the cost of employee health care and is pressing for a redesign of the health delivery system.[32]

The structure of current insurance programs has precluded access to appropriate health insurance coverage for up to one third of all Americans under the age of 65. As Butler et al[33] have pointed out, this problem "stems primarily from the American system of employer-provided health insurance." Although no single approach will solve all the ills of the insurance crisis, the creation of statewide groups using the school system as the grouping mechanism could make

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important progress toward the provision of coverage to uninsured or underinsured people. Such a program, though not providing universal coverage, might relieve many of the complex financial and social problems attendant on the current distribution of health insurance coverage.

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INTERIM REPORT

Healthy kids

FLORIDA HEALTHY KIDS CORPORATION

345 S. Magnolia Drive, Suite E-17 • Tallahassee, Florida 32301 • 904/878-8566

This Interim Report is provided to the Governor, Insurance Commissioner, Commissioner of Education, Senate President, Speaker of the House of Representatives, Minority Leaders of the Florida House of Representatives and the Florida Senate and other interested persons, by the Florida Healthy Kids Corporation and its Board of Directors as required by 624.91, Florida Statutes, the Healthy Kids Corporation Act.

BACKGROUND

In 1988, an article was published in the New England Journal of Medicine which first described the concept of School Enrollment-Based Health Insurance.

The Institute for Child Health Policy at the University of Florida received grant funding from the Maternal and Child Health Bureau under the U.S. Public Health Service and from Robert Wood Johnson, a private foundation, which financed further study of the concept. With this financing, the Institute began product research and development with Medimetrix Group, a health care consulting firm.

In 1990 the Florida Legislature, at the urging of the state commissioners of insurance and education, passed the Healthy Kids Corporation Act which became law July 1, 1990. This was in response to the rising number of uninsured families and children in the state and overwhelming statistics evidencing a decline in child health and preparedness for learning.

The proposed Corporation was given two missions: to create a comprehensive insurance product for school children and to facilitate the provision of preventive care for all children. These two primary assignments were the foundation upon which the Corporation began operations.

With its creation in November 1990, work began on the product design and administrative structure of the Corporation.

A joint proposal was prepared and forwarded to the Health Care Financing Administration by the Florida Medicaid Program, the Institute for Child Health Policy and Healthy Kids. This proposal described the school enrollment-based health insurance concept which would provide free and reduced price health insurance for school children based on their eligibility for the school lunch program. The HCFA selected the joint proposal and a four-year cooperative agreement was established. The grant has helped to fund program development and administration during the past year and release of these funds to provide subsidized premium is currently pending. State and private contributions are required to ensure the flow of these federal dollars. A mechanism which could provide some subsidy of premium for families with incomes above 185% of the federal poverty level is also desired.

Initial program implementation has been broken into three phases. Phase one, which has begun, covers the school age child; Phase two, which will begin in the Fall of 1992, will cover the preschool age siblings and dependents of the school child; Phase three, for which no date has been set, may extend coverage to the parents of these children in the future.

There is considerable interest in what we, in Florida, are doing as is evidenced by recent national wire service stories as well as radio and television coverage about the program. After contacting us, other states have introduced laws similar to the Healthy Kids Corporation Act and Congress is currently considering bills which reference school-based programs such as this.

WHAT IS SCHOOL ENROLLMENT-BASED HEALTH INSURANCE?

Traditionally, Americans have obtained individual and family health insurance coverage in one of three ways. Some have been covered by public programs, and some have paid directly for policies, but by far the largest number of people have obtained health coverage in the form of group insurance provided through their employers. Insurance programs for members of large employer groups have had the lowest prices. Because employers typically pay for coverage of individual workers rather than families, children as a group are disproportionately uninsured.

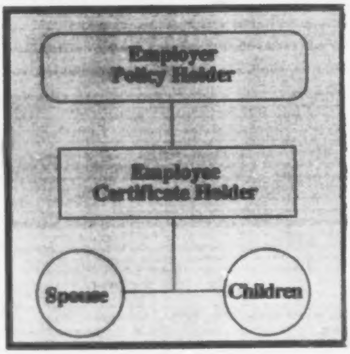
500,000 of Florida's school children are uninsured

It is estimated that approximately 500,000 of Florida's school children are uninsured. The chance of being uninsured is 37% higher for a child than an adult. In addition, a lack of insurance coverage translates directly to a lack of health care. Uninsured persons use medical care less often than do insured, and they are more likely than the insured to be in poorer health. In a recent study of Florida families with children, it was found that uninsured children had hospital lengths of stay nearly twice that of insured children.

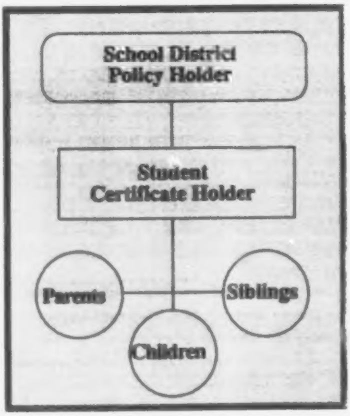
School systems are used as grouping mechanisms

An alternative is school enrollment-based health insurance. To enhance access to health care for children, state school systems are used as grouping mechanisms for negotiating preventive care and comprehensive group health insurance policies. Coverage will be offered to all families with children enrolled in school. Policies are currently designed to accommodate the school child. Coverage could be extended to dependents, non-school age siblings and the parents of these children in the future.

Traditional Model



School Enrollment-Based Health Insurance Model



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THE CORPORATION

Staffed by experienced insurance and managed health care professionals, the Corporation is the facilitator which brings together all parties involved in this project. The Board of Directors is representative of insurance and insurance regulatory officials, school health and school administration officials, private physicians, public health programs and universities.

The **Florida Healthy Kids Corporation**, through its staff and subcontractors, provides the administrative functions of the project. By providing these functions, administrative costs built into the premium are currently less than 2%. Private contributions by local businesses toward printing and marketing have been key in the effort to keep administrative costs down.

Healthy Kids Partnership in Volusia County:
Florida Healthy Kids Corporation
BTI Services, Inc.
Florida Health Care Plan, Inc.
Institute for Child Health Policy
Local Steering Committee

The Corporation was designed to operate with very few staffed positions. A significant amount of the inner workings have been contracted to private market companies.

A records administrator was hired by the Corporation to assist with many of the enrollment functions. **BTI Services, Inc.** provides assistance with eligibility determination, and monthly premium collection. A coupon book is provided to those families making monthly contributions to the premium and on-line enrollment information is available to the Corporation. The records administrator also provides extensive computer capabilities without the associated investment the purchase of equipment would require.

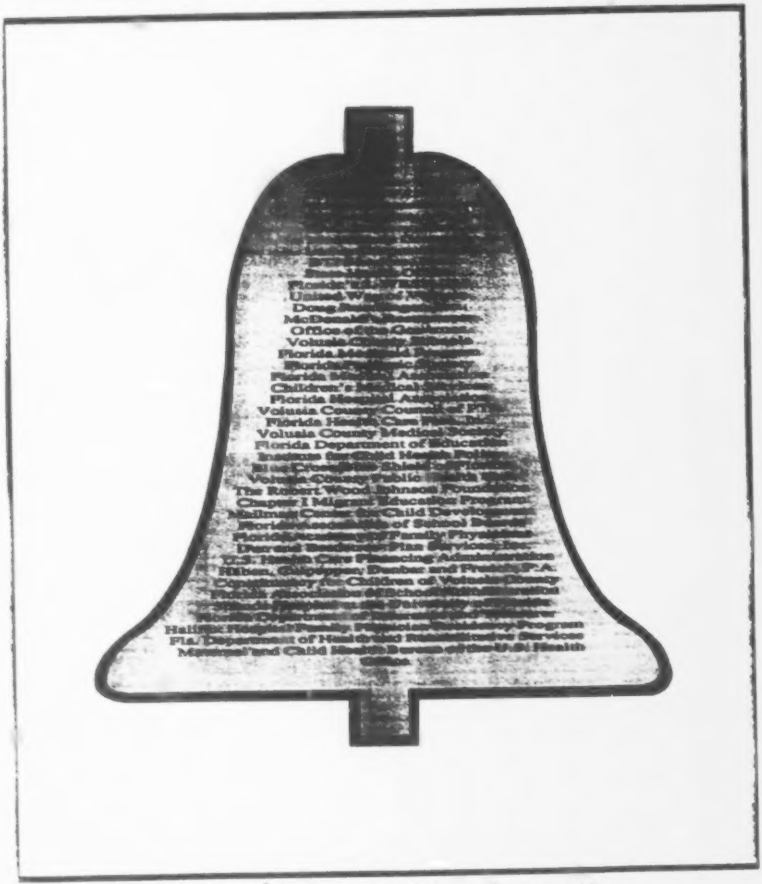
Florida Health Care Plan, Inc. provides the physician network and health services required for the program in the first county. Enhancement of the existing provider network was necessary to accommodate the anticipated increase in pediatric members. Pediatricians and family physician members of the county medical society have joined with the health plan to provide a geographically appropriate network of health care providers. In addition, a new pediatric facility was designed, equipped and staffed in order to better serve Healthy Kids.

The Institute for Child Health Policy will provide an evaluation of the program's effectiveness. Annual surveys will be performed in each pilot site and the program's impact on the health status of children will be measured. In addition, school enrollment trends will be monitored as well as the frequency of emergency room visits by this population.

It was widely acknowledged by the Board that programs of this type require local input. In order to gain the input of the local community, the Volusia **Steering Committee** was established. Chaired by Ms. Linda Merrell, this active group brings together local medical society members, child advocates, the health care provider, the county public health office, local school officials and representatives of the business community. The common goal of this diverse group is that children gain access to health care and be better prepared for learning.

The Steering Committee makes recommendations to the Board on areas of critical local concern and has helped to shape the projects' design. Contributions are being sought by this group for scholarships and a rescue fund to assist families who have difficulty making regular monthly premium contributions. This committee developed a new member orientation to help better educate parents on how to gain access to medical care for their children and to increase community awareness about the program. The efforts of this group are considered to be a key to local program success.

When the school bells rang in Volusia County this Fall, many organizations had already stepped forward to ensure that students would have greater access to health care services.


Florida Medical Association
Children's Medical Services
Florida Hospital Association
Volusia County Medical Society
Florida Department of Education
The Robert Wood Johnson Foundation
Chapter I Migrant Education Program
U.S. Health Care Financing Administration
Fla. Department of Health and Rehabilitative Services

Healthy kids: A Public-Private Partnership

THE SCHOOLS

In order to implement a school enrollment-based project, cooperative school districts were sought. The Corporation solicited interest from Florida school districts and reviewed proposals for participation. Ten school districts were selected as potential pilot sites.

Volusia County was selected to be the first site implemented due primarily to its urban/rural mix and population size. Innovative programs already in existence in the county and the evidence of a cooperative medical and business community were also important factors for site selection.

Future
Healthy Kids
Pilot Sites
ALACHUA
COLLIER
DADE
DUVAL
HIGHLANDS
HILLSBOROUGH
LEE
LEON
PINELLAS

The part played by the school district is varied in this project. School district personnel provide assistance with the family health and insurance survey, offer school facilities for use by the Corporation, and formally endorsed the program. A very important part of the schools' involvement has been to put staff in touch with community leaders and business groups. Each school was asked to appoint a contact person to assist with distribution and collection of enrollment and marketing materials, to assist families with completing the forms and to answer questions applicants may have. School contacts provide families with a familiar face with which to consult. School personnel have acted as interpreters and translators, made facilities available for meetings and orientation programs for families signing up and have agreed to allow the performance of initial health assessments on participating children on school premises if the family chooses to have one.

Essential to the project, is the districts' ability to verify student participation in the national school lunch program and other eligibility criteria. School personnel will advise Healthy Kids of those students who drop out of school, making them ineligible for the program. All families participating in the program have signed authorizations for the release of this information.

Schools can put us in touch with children whom they may have identified as potential participants. School nurses help to identify these children.

In addition, the school district may provide birth date information on students in order that they may receive a card reminding them when they are due for a wellness check.

Schools have provided mailing labels to assist the Corporation with marketing efforts and allowed use of their dial-up system which automatically calls a student's home with a prerecorded message. These systems are frequently used to notify parents of a child's absence from school and have been made available to the Corporation.

These activities have required a tremendous commitment from school board members and district personnel. Similar assistance and involvement will be necessary for programs implemented in other school district sites. The degree of commitment is an important measure in future site expansion.

School Involvement Includes:

- **verify school enrollment and age information**
- **verify lunch program participation**
- **endorse the program**
- **distribute applications and marketing materials**
- **allow use of school contacts**
- **conduct annual survey**
- **keep in touch with the community**
- **provide parent outreach**

THE MOST FREQUENTLY ASKED QUESTIONS:

Who is eligible?

Children must:

- be actively attending school
- be age 5-19
- be uninsured for six months
- be ineligible for public programs

What are the covered benefits?

The services were designed with children in mind and with an emphasis on preventive care. Health benefits include:

Well Child Care Visits & Immunizations
Primary & Specialty Physician Office Visits
In-Patient Hospital Care
Surgical Procedures
Emergency Services & Transportation
Prescriptions
Vision Screening & Glasses
Hearing Screening & Hearing Aids
Physical Therapy
Mental Health Services

What about pre-existing conditions?

There are no limitations on coverage for pre-existing conditions. No health questions are asked of applicants and there is no waiting period.

Are there out-of-pocket expenses?

There is no charge to the patient for doctor office visits or hospital stays. Some co-payments are required for emergency services, prescription medicines and mental health services.

For a complete schedule of benefits and co-payments, please contact the Corporation.

Which doctors will kids see?

In Volusia County, services will be delivered by Florida Health Care Plan, Inc., a local health maintenance organization. Families will select a primary care physician who will manage their child's care. An extensive network of primary and specialty physicians has been developed for this population.

How much is the premium?

In Volusia County, costs are determined by family income. In order to keep administrative costs in line, family income is determined to be that which is reported to the school for participation in the National School Lunch Program. By doing so, the Corporation is eliminating the need for a separate, time consuming and more costly system of determining income eligibility. Determination of income is only necessary for those families wishing to apply for help in paying their premiums.

Monthly per child costs in one pilot site:

0-100% FPL	FREE
101-135% FPL	$3.00
136-185% FPL	$16.00
186% FPL and up	$60.00

How do families sign up?

At least one open enrollment period will be held each school year. The initial enrollment of children in Volusia County began February 1, 1992. Coverage will be in effect through the summer with a renewal period and second open enrollment period scheduled for each Fall thereafter.

Applications are distributed and collected at the schools. Once eligibility has been confirmed, families receive membership handbooks and select their primary care provider.

How will this program be expanded?

Additional sites, when implemented, may require a different scale of payment depending on local factors such as medical costs and availability of local funds or other grants. The administrative structure is designed to accommodate different •premium levels depending on local needs. This is a key element to implementation of a statewide program.

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Prepared Statement of the March of Dimes Birth Defects Foundation, Washington, DC

The March of Dimes shares the concern about the growing number of uninsured Americans and the increasing cost of health care which have been expressed by other voluntary health organizations and professionals, as well as business, labor, and elected leaders. The mission of the March of Dimes is to improve the health of babies by preventing birth defects and infant mortality. Thus, we have a special interest in the barriers to access to care faced by millions of American families who want to have healthy babies.

I. We know that problems result from our nation's failure to ensure universal access to health care.

The nation simply cannot afford to continue on its present course. This is especially true if we are to make good on our moral and ethical responsibilities to ensuring that babies are born with the greatest chance of survival.

o Each year, nearly 40,000 infants die before their first birthday. More than 8,000 of these die as a result of a birth defect and thousands more die from low birthweight (less than 5.5 pounds).[1]

- The White House Infant Mortality Task Force estimated that every infant death represents $380,000 in lost productivity and that one-quarter of the total number of infant deaths could be prevented with the knowledge and technology now available.[2]

Our national policies and these resulting statistics reflect a half-hearted commitment to improving infant health and survival. Inadequate access to health care for pregnant women and infants is a primary factor contributing to our poor international standing in maternal and infant health. Experts tell us of the importance of access to high quality maternity care, that begins with prenatal care in the first three months of pregnancy, but the nation has failed to heed the call.

- We have made no progress in improving early prenatal care use since 1979. A decade ago, one-quarter of all pregnant women received no prenatal care in the critical first three months of pregnancy. That figure has not changed.
- In 1989 more than 85,000 babies were born without benefit of any prenatal visits -- this means that their mothers did not see a health provider before they arrived at the hospital to give birth.[3]

When we fail to ensure access to care for pregnant women and children, we miss opportunities to prevent costly health problems. When families delay preventive care, society pays.

- Prenatal care has been found to be effective and cost effective -- saving $3 for every $1 invested by improving infant health and reducing neonatal intensive care costs.
- Neonatal intensive care is among the most costly of all hospital services, and related hospital bills often go unpaid because infants are uninsured. About one-quarter of unpaid hospital costs are for maternity and newborn care.[4]
- Immunizations, beginning in infancy and delivered on time

> can save $10 for every $1 invested. We pay more when infants do not receive vaccines and a case of preventable whooping cough or measles is the result.

It is obvious that health status and utilization are linked to many factors. However, insurance is the first critical step in assuring access to services. In a landmark report on prenatal care, the Institute of Medicine reported that:

> "Financial barriers -- particularly inadequate or no insurance and limited personal funds -- were the most important obstacles reported in 15 studies of women who received insufficient care."[5]

From New York City to Oklahoma City, these studies document the financial barriers that keep women from receiving early and adequate prenatal care.

II. The Inadequacy of Current Insurance Coverage

As the number of uninsured Americans has grown in recent years, women of childbearing age and children experienced a disproportionate impact. Workers' children and dependent spouses often are excluded from employer-based health insurance plans. Young families rarely can afford to buy the additional coverage which may cost $3,000 or more per year. As a result they live uninsured or underinsured. Consider these facts:

- In 1990, despite recent expansions of Medicaid, an estimated **443,000 pregnant women had no health insurance.**[6] That year, over 8.4 million women of childbearing age had no health insurance; of these, 6 million were working women.[7]
- Nearly two-thirds of the uninsured are concentrated in low-income families. The majority live in two-parent, working families with children. The typical woman having a baby is from such a family -- she is in her twenties, married, family income of just under $20,000 per year, with at least a high school education, and employed, or married to a man who is employed, full-time.[8]

- Between 1980 and 1985, the proportion of children under age 18 covered by employer insurance fell by 6 percent (from 64.6 percent to 60.6 percent). Among poor children under age 18, the proportion privately insured declined by one-quarter, from 16.9 percent to 12.8 percent.[9]

The problems of being uninsured are most serious for low income families who cannot afford to pay for care "out-of-pocket." For example, when a pregnancy occurs the need for care is urgent but may go unmet. The average bill for having a baby is estimated at over $4,000. This conservative estimate, that assumes there are no complications, represents one-fifth of the average income of a couple in their early twenties.

Furthermore, the concept of insurance is eroding. Many of the sickest populations have been left behind. At the same time, the preventive care needed by pregnant women and infants often is left out of private employer-based benefit packages.

- An estimated **5 million women of childbearing age have private insurance that does not cover maternity care.**[10] This means that prenatal care already is outside of the scope of coverage for thousands of pregnant women each year.
- Uninsured women often cannot afford to purchase "out-of-pocket" the basic services that might have given a baby a chance to survive, such as genetic screening or prescription drugs to treat sexually transmitted diseases.
- Infants born with a birth defect may have conditions that are excluded categorically from insurance plans. For those who survive, health care coverage may not be available to meet the cost of remedial care that could prevent or limit disabilities.

III. What action must be taken in response to these problems?

The March of Dimes strongly believes that the unique needs of pregnant women and infants must be considered in the health care reform debate. To that end, the Foundation has supported

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the work of an expert panel of the National Academy of Sciences, National Forum on the Future of Children and Families that released a report last month which examines health policy issues presented by children and pregnant women that should be addressed as part of the health care reform debate. The panel set out 11 principles for evaluating the adequacy of health care reform proposals in relation to maternal and child health.[11] The report, "Including Children and Pregnant Women in Health Care Reform," has brought to light many questions about how the nation can improve the health of pregnant women and infants.

In the broad health care reform debate, the March of Dimes believes that:

1) Any health care reform proposal should provide affordable and user-friendly health care coverage for all pregnant women and infants.

2) A health care reform plan should define a basic set of benefits for pregnant women and children, with emphasis on prenatal care and other preventive services.

3) Health care reform legislation should include a plan for improving the supply and distribution of maternity and pediatric providers.

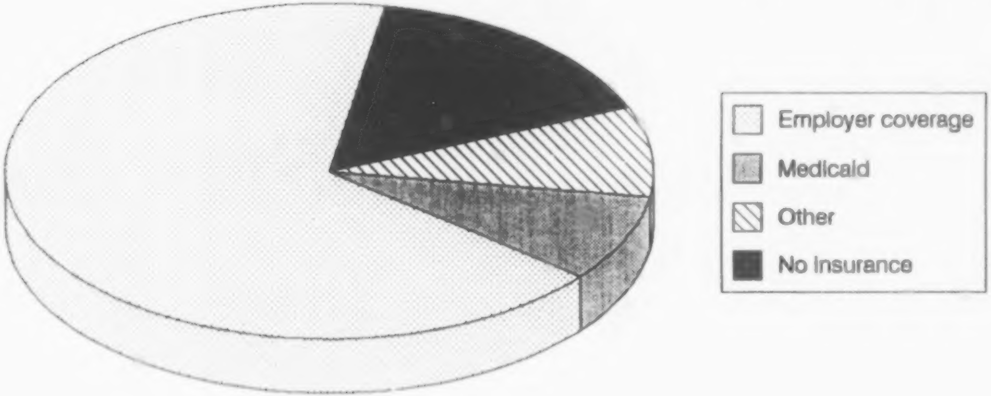
4) Health care reform legislation should contain mechanisms to coordinate funding streams, contain costs, and assure quality to protect the health of mothers and infants.

These principles of the March of Dimes support the view that a primary goal in health care reform is universal coverage for pregnant women and infants. At the same time, our principles recognize that while insurance reform is a start, it alone cannot solve the crisis in access to care. In addition, millions of families live in communities where there are no maternity or pediatric providers.

We understand that there are no easy answers to the current crisis in health care. At the same time, we urge Congress to act thoughtfully and expeditiously to ensure access to care for all Americans and to give priority to actions that can improve infant health and survival.

Figure 1

Health Insurance Status of Women of Childbearing Age, 1990



Source: Current Population Survey analysed by
Employee Benefit Research Institute

March of Dimes, 1992

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TO: The Honorable Pat Schroeder, Chairperson
Members, House Select Committee on Children Youth and Families

FROM: Dr. Richard H. Flyer, Chair
Reginald S. Dorsey, Member
Emergency Medical Services for Children Coalition (EMSCC)

DATE: May 15, 1992

RE: **EMERGENCY MEDICAL SERVICES FOR CHILDREN (EMSC)**

The Emergency Medical Service for Children Coalition (EMSCC) is a statewide coalition made up of advocates, pediatricians, nurses, state department personnel and others that have come together in support of legislation to establish an emergency medical services for children program on behalf of New Jersey's children and families.

EMSCC members have participated and are presently active on various coalitions and advisory councils that are concerned with maternal, child and infant health issues. The present coalition has organized in response to the recognition of an inadequate emergency medical services system for children in our state. Members strongly feel that now is the time for New Jersey to develop and implement a comprehensive and coordinated system of specialized pediatric services and EMSC components.

INJURIES -- THE MOST TRAGIC REALITY FOR OUR CHILDREN

According to Antonia C. Novello, US Surgeon General, about 40 percent of the deaths among children under 4 and 70 percent of deaths among older children are due to injuries. Injuries are the leading cause of death among children today, with nonfatal injuries outnumbering fatal injuries. Annually, injuries claim the lives of over 22,000 children between the ages of 0 and

19 years. Each year, an estimated 600,000 children are hospitalized, and almost 16 million more are seen in emergency rooms for their injuries. The toll of injuries on the young is devastating; they suffer more deaths from injuries from the first year of life through the age of 19 than from all diseases combined.

Injuries are also the leading cause of disability, with more than 30,000 children suffering permanent disabilities each year. Although the effects of such disabilities on children's development, daily living, and future productivity are great, the financial, emotional and social effects on the family are enormous.

In New Jersey, approximately 10% of the calls for paramedics are for pediatric services. Twenty-five to thirty-five percent of emergency department visits in many areas of this state are for pediatric patients. Community hospitals often lack the clinical resources and equipment or they don't have sufficient caseloads to warrant specialized staff for child emergencies. Many emergency vehicles are not adequately equipped with special sized equipment for children. The death rate of children in the field and emergency departments in hospitals is almost twice that of adults. Because of a lack of Emergency Medical Services for Children, a number of New Jersey's most valuable and precious resource, our children, die or suffer permanent disability needlessly each year.

MEETING THE EMERGENCY MEDICAL SERVICE NEEDS OF OUR CHILDREN

Perhaps the biggest concern is that many doctors, nurses, paramedics, and emergency medical technicians continue to treat children as miniature adults. The life saving techniques that work in the field, in emergency rooms and in intensive care units for critically ill and injured adults cannot be directly transferred to the care of critically ill and injured kids. For example, medical doses are different, airway sizes are different and intravenous lines are different, to name a few.

Improving the system to better meet the emergency needs of children will take an intense effort on the part of government, physicians, and parents. The development and implementation of a comprehensive, coordinated emergency medical services system for critically ill and injured children requires 3 elements:

1. **Prehospital Services** - Ambulance crews must have the equipment and training to provide proper care to children and the most accurate information to help direct young patients to facilities that can provide the most appropriate care.

2. **Emergency Room and Intensive Care Systems** - Hospital emergency rooms that receive such children must have emergency care specialists who are well versed in pediatric care, with the necessary equipment to back them up to assure that children who require intensive care are being treated by pediatric units rather than adult units.

3. **Rehabilitation Services** - Rehabilitation units must be staffed with rehabilitation specialists expert in treating children and capable of providing any service required to assure maximum recovery from the physical, emotional, and cognitive effects of critical illness and severe trauma.

LEGISLATION ESTABLISHING EMERGENCY MEDICAL SERVICES FOR CHILDREN (EMSC) PROGRAM

On February 24, 1992, Senator James Cafiero introduced legislation that would establish an Emergency Medical Services for Children Program within New Jersey's State Department of Health (Senate Bill 408). Senator Cafiero's bill would require the implementation of a statewide comprehensive and coordinated emergency medical service system for children. An Emergency Medical Services for Children Advisory Council, created by the bill, would monitor and have the oversight of this critically needed system.

This legislation addresses the 3 critical elements of a comprehensive program. The EMSC Program would also include, among other things: 1) initial and continuing education programs for emergency medical services personnel that include training in the emergency care of infants and children; 2) guidelines for referring children to the appropriate emergency treatment facility; 3) pediatric equipment guidelines for pre-hospital care; 4) guidelines for hospital-based

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emergency departments appropriate for pediatric care to assess, stabilize, and treat critically ill infants and children; 5) guidelines for pediatric intensive care units, pediatric trauma centers, and intermediate care units fully equipped and staffed by appropriately trained critical care pediatric physicians, surgeons, nurses and therapists; 6) an inter-hospital transfer system for critically ill or injured children; and 7) pediatric rehabilitation units staffed by rehabilitation specialists and capable of providing any service required to assure maximum recovery from the physical, emotional, and cognitive effects of critical illness and severe trauma.

SUPPORT FOR A COMPREHENSIVE, COORDINATED EMERGENCY MEDICAL SERVICES FOR CHILDREN PROGRAM

The fact that everyday, some of America's children die, almost die or suffer needlessly from being permanently disabled because they are taken to the wrong hospital, treated with improper equipment, given wrong dosages of medications or not diagnosed properly, speaks to the necessity of developing a comprehensive and coordinated emergency medical services for children program. A report by the National Center for Education in Maternal and Child Health declared, "The majority of infant, children and young adults who might benefit from pediatric critical care services do not receive them...[also] in communities without access to specialized pediatric services and EMSC system components, there is a higher mortality rate for critically ill and injured children."

New Jersey has made some tremendous strides in addressing the health care needs and prioritizing prevention efforts for our children through various initiatives such as the Medically Needy Program, HealthStart, The Catastrophic Illness Relief Fund and most recently, requiring children 14 years and under to wear bike helmets. However, there is much more to do. If only one child and one family suffers from a traumatic experience that could have been prevented by an appropriate system of medical services, then that suffering is one too many.

New Jersey has the opportunity to take a major step in the medical care of its children. Senate Bill 408 establishing medical services for children program takes an important step toward improving the critical care needs of the children of our State for years to come. The Emergency

Medical Services for Children Coalition strongly supports the passage of S-408 and will do what it takes to see to it that the children of our state have access to a comprehensive and coordinated system of pediatric services to assure them the healthiest life possible.

Unfortunately, the critical care needs of New Jersey are true for many, if not all, states across the nation. This is a crisis that needs to be met on the federal level. Congresswoman Schroeder, and members of the House Select Committee on Children Youth and Families, we are asking you to consider the following as the basis for federal action for emergency medical services for children:

1) The New Jersey legislation and proposed program is based upon a federal grant that will provide the "start-up" funds for the emergency medical services program. It is hopeful that in two years, after the federal funds have been utilized, that the State will take the responsibility of funding the critical care program for children. We encourage this committee to explore the possibility of a start-up fund for states to establish similar programs as proposed in New Jersey.

2) The strength of the New Jersey proposal is that it provides a comprehensive coordinated system of standards for pediatric services. Along with the start-up funds, the federal government should outline standards for meeting the critical care needs of children to provide direction for state initiatives.

The opportunity to make a tremendous impact on the critical care needs of our children is upon us now. We strongly encourage this committee to consider our recommendations for federal action. As stated above, our Coalition is available to help and assist in anyway possible for the health of our children.

ONE HUNDRED SECOND CONGRESS

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May 21, 1992

Richard P. Nelson, M.D., Director
Iowa Child Health Specialty Clinics
HS-247 University Hospital School
Iowa City, IA 52242

Dear Dr. Nelson:

I want to express my personal appreciation to you for appearing before the Select Committee on Children, Youth, and Families at our hearing, "Health Care Reform: How Do Women, Children, and Teens Fare?," on May 2, 1992. Your testimony was important to the work of the Committee.

The Committee is now in the process of preparing the transcript for printing. It would be helpful if you would go over the enclosed copy of your remarks to assure that they are accurate, and return the transcript by Monday, June 1, with any necessary corrections.

In addition, I would appreciate a response in writing to the following questions for inclusion in the record:

1. Are there any state Maternal and Child Health initiatives that stand out in your mind that are already meeting the criteria you described in your framework? Any state efforts that are improving access to preventive and comprehensive care for teens in particular?
2. Which of the proposals you analyzed would benefit or ameliorate the problems experienced by each of our families who testified at the hearing?

Sincerely,

Pat Schroeder

PATRICIA SCHROEDER
Chairwoman
Select Committee on Children,
Youth and Families

RESPONSE FROM RICHARD P. NELSON, M.D., TO QUESTIONS POSED BY CHAIRWOMAN PATRICIA SCHROEDER

June 4, 1992

The Honorable Patricia Schroeder
Chairwoman
Select Committee on Children,
Youth and Families
Attn: Jill B. Kagan
U.S. House of Representatives
Room H2-385 Annex 2
Washington, D.C. 20515-6401

Dear Representative Schroeder:

Thank you for the opportunity to further comment on how health care reform will affect women, children, and teens. I am writing in response to your request of May 21.

There are many initiatives supported by state Title V maternal and child health programs that are consistent with the criteria described in our framework for the analysis of health care reform proposals, including innovative service delivery models fostered and supported by state MCH programs. In Colorado, for example, there are seven distinct projects targeted to adolescents that are funded through the MCH block grant; some are focused on education, others on health and support services. These projects are involved in a variety of activities, including training and support for volunteers in several communities who provide workshops to adolescents around the development of self-responsibility and communication skills. Another nationally known program that is almost statewide provides comprehensive school health education through training teachers to work with students on health decision making. Several programs target high risk pregnant and parenting teens, offering both preventive services and clinical care. Support is also provided for the Denver School Based Clinics System. (A recent study of fourteen school-based programs, including Denver's, found that eleven of them were at least partially funded by federal or state MCH funds; in five of the programs, the MCH funds were the primary source of funding.) The Colorado Department of Health estimates that over 86,000 adolescents benefitted from Title V supported services during a recent fiscal year. During the current fiscal year new multiagency collaborative projects were anticipated in Colorado, including an effort to provide intensive intervention to all teen parents in Boulder County, and a mall-based Youth Services site to provide health education and counseling, as well as job referrals for high risk youth, many of whom are dropouts. The Colorado MCH program's successes in facilitating community-based innovative programs for adolescents have been recognized by the award of a grant from the federal MCH Bureau for the state to serve as a resource center to other states. Similar programs and services can be found in many other states. These programs, using Title V, state and local public health funds, are designed to reach at risk populations and provide a range of services that are not generally available through individual health care practitioners, and require organization and planning. They are comprehensive and preventive in nature, based on an understanding that common issues and needs underlie the various manifestations of teen health problems--whether there be teen pregnancy, substance use or violence.

You also requested that we comment on how the current legislative health care reform proposals would benefit or ameliorate the problems experienced by families who lose their source of health care financing due to the high utilization (and therefore high cost) of health care required by a family member, or who are uninsurable if their employer's policy lapses or coverage is converted to another company. The bills analyzed by AMCHP using our maternal and child health framework would apparently provide some protection. The bills assure the ability to continue coverage and to convert coverage. Each of the four bills analyzed within the framework (Matsui, Russo, Rockefeller and Stark) would furthermore provide coverage for catastrophic care without a lifetime cap on benefits. A major issue in implementing any of these proposals, however, would center on whether premiums are affordable for families when cost-sharing is required. On the other hand, the proposals provide little support to families of children with chronic health conditions who require support services to benefit from health care, such as assistance with the costs of transportation when necessary services are provided at a distance from their home, support for regionalized specialty services that would be more accessible to families in rural or less populated areas, and other family support services (such as home visiting and respite care) for special populations. These latter services are often essential to maintain the overall health and well being of families as they struggle to care for the child with special health care needs and at the same time maintain other aspects of family function.

As legislative proposals are further developed and refined we would be pleased to offer specific comment on these issues and have appreciated the opportunity to provide this information.

Sincerely,

Richard P Nelson

Richard P. Nelson, M.D.
President

RN:bjk

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May 21, 1992

Robert Johnson, M.D., Director
Adolescent and Young Adult Medicine
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185 South Orange Avenue
Newark, NJ 07103-2757

Dear Dr. Johnson:

I want to express my personal appreciation to you for appearing before the Select Committee on Children, Youth, and Families at our hearing, "Health Care Reform: How Do Women, Children, and Teens Fare?," on May 2, 1992. Your testimony was important to the work of the Committee.

The Committee is now in the process of preparing the transcript for printing. It would be helpful if you would go over the enclosed copy of your remarks to assure that they are accurate, and return the transcript by Monday, June 1, with any necessary corrections.

In addition, I would appreciate a response in writing to the following questions for inclusion in the record:

1. You described a variety of appropriate health care settings for adolescents. Would all of these settings work in every community or should particular communities decide which model works best for them? Do all of the settings you described meet your criteria for supplying providers who are well-trained in adolescent development and adolescent medicine? Do they all meet your criteria for meeting the __immediate__ needs of adolescents?

   What about college health services that have been around for years? Do they provide an appropriate model of care for teens?

2. You mentioned that one barrier to care is the insurance company requirement that beneficiaries identify themselves with a card -- and teens can't always do this. Should we mandate in any health care bill that moves forward that adolescents in the family be given their own insurance card? Don't we need to do this in concert with modifying parental consent laws so that teens can have confidential access to general health care services? How would we overcome parental objections? political objections?

Sincerely,

Pat Schroeder

PATRICIA SCHROEDER
Chairwoman
Select Committee on Children,
Youth and Families

Enclosure

RESPONSE FROM ROBERT L. JOHNSON, M.D. TO QUESTIONS POSED BY CONGRESSWOMAN PATRICIA SCHROEDER

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Division of Adolescent Medicine
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Newark, NJ 07103-2714

May 29, 1992

The Honorable Patricia Schroeder
Chairwoman
Select Committee on Children,
Youth and Families
U.S. House of Representatives
385 House Office Building Annex 2
Washington, DC 20515-6401

Dear Ms. Schroeder:

I have reviewed the transcript of my testimony before your committee and I have no substantive changes.

1. You described a variety of appropriate health care settings for adolescents. Would all of these settings work in every community of should particular communities decide which model works best for them?

Response:

In my testimony, I described a variety of health care settings all of which have the capacity to comprehensively and holistically respond to the health care needs of adolescents; however, communities may vary in their need to and their capacity to develop these services. For example, a large comprehensive service center such as The Door in New York City may work very well in other large cities but it may not be feasible in rural communities where there are fewer adolescents and shortages of professionals to provide the services. Individual communities should assess their needs and capacities and develop the health care setting which are specificallyappropriate for their adolescent populations.

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Do all of the settings you described meet your criteria for supplying providers who are well trained in adolescent development and adolescent medicine?

Response:

The settings which I have described all have the capacity to meet the criteria I set forth relative to supplying providers who are well-trained in adolescent development and adolescent medicine. However, since this training currently exist only in Pediatrics, other practitioners who intend to care for adolescents should e given the opportunity to attend training workshops where they could develop specialized skill in Adolescent Health.

Do they all meet your criteria for meeting the immediate needs of adolescents?

Response:

Each health care model has the capacity to provide the support necessary for the health of our adolescents. Given the financial and legal access necessary, each model has the capacity to provide excellent adolescent care.

What about college health services that have been around for years? Do they provide an appropriate model of care for teens?

Response:

In my experience, most college health services are designed to provide episodic care rather than comprehensive health care. Therefore, they are usually not appropriate models for this consideration.

2. You mentioned that one barrier to care is the insurance company requirement that beneficiaries identify themselves with a care - - and teens can't always do this. Should we mandate in any health care bill that moves forward that adolescents in the family be given their own insurance card?

Response:

Yes, a health care bill that provides adolescents with their own insurance card would remove an important barrier to access. Ideally, every family member covered under the insurance policy should have his/her own insurance card.

Don't we need to do this in concert with modifying parental consent laws sos that teens can have confidential access to general health care services? How would we overcome parental objections? political objections?

Response:

The rules and regulations which currently govern a minor's right to consent to health care is a confusing patchwork of statutes, torts, supreme court decisions, administrative regulations, and traditions. Federal efforts are needed to encourage states to clarify to interpretations of the current "consent laws" and broaden the health enfranchisement of adolescents. In my experience, parents have not objected to these proposals when it is made clear that this is not an attack on parental authority or the integrity of the family. Obviously, the accurate appreciation of these proposals will require education and enlightenment.

If I can be of further assistance, please do not hesitate to contact me.

Sincerely,

Robert L. Johnson, M.D., F.A.A.p.
Professor of Clinical Pediatrics
Associate Professor of Clinical Psychiatry
Director of Adolescent Medicine

RLJ/me

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May 21, 1992

Edmund F. Haislmaier
Health Care Policy Analyst
Heritage Foundation
214 Massachusetts Ave., N.E.
Washington, DC 20002-4999

Dear Mr. Haislmaier:

I want to express my personal appreciation to you for appearing before the Select Committee on Children, Youth, and Families at our hearing, "Health Care Reform: How Do Women, Children, and Teens Fare?," on May 2, 1992. Your testimony was important to the work of the Committee.

The Committee is now in the process of preparing the transcript for printing. It would be helpful if you would go over the enclosed copy of your remarks to assure that they are accurate, and return the transcript by Monday, June 1, with any necessary corrections.

In addition, I would appreciate a response in writing to the following questions for inclusion in the record:

1. Your proposed health care reform program is targeted at individuals who work for employers. How do you propose to provide health care coverage for individuals who do not fit into this category, such as college students, seasonal workers, those who are self-employed or who work on commission?

2. In your proposal there are several health insurance regulation reforms to control rapid increases in the cost of premiums. How do you plan to prevent insurance companies from shifting more of the cost of health care to the consumer by limiting the scope and extent of what they will pay?

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3. How would your proposal help the families who testified at the hearing? How does your proposal meet the goals and criteria outlined by Ms. Brown and Dr. Nelson to meet the special needs of women, children and teens in gaining access to the health care system?

Sincerely,

Pat Schroeder

PATRICIA SCHROEDER
Chairwoman
Select Committee on Children,
Youth and Families

Enclosure

RESPONSE FROM EDMUND F. HAISLMAIER, TO QUESTIONS POSED BY CONGRESSWOMAN PATRICIA SCHROEDER

Q: Your proposed health care reform program is targeted at individuals who work for employers. How do you propose to provide health care coverage for individuals who do not fit into this category, such as college students, seasonal workers, those who are self-employed or who work on commission?

A: As noted in my testimony, one of the principle objectives and effects of our reform proposal would be to end the present link between health care and employment. The current system provides tax relief almost exclusively for medical care purchased through employer-sponsored health insurance. In contrast, our proposal would provide health care tax relief directly to Americans instead of through their employers. Under our proposal, individuals and families would themselves decide:

1) What part of their medical expenses to purchase directly out-of-pocket and what potential expenses to buy insurance protection against. In other words, how comprehensive they wanted their insurance coverage to be.

2) Which insurance plan to purchase and whether to purchase it on their own or through a group. There are often wholesale purchasing advantages for buying insurance, or anything else, through a group. But because the tax benefits under our proposal go directly to individuals and families, people could purchase coverage through any group, not just employers, and still receive health care tax relief.

In addition, the size of the tax relief would vary based on an individual or family's total health expenses (both out-of-pocket payments and insurance premiums) relative to income. Those with lower incomes and/or higher health expenses would receive proportionately more tax relief.

Therefore, these reforms would be particularly advantageous to the many people who are currently discriminated against by the present policy of tying health care tax relief to employer-sponsored insurance, including those you asked about -- namely, college students, seasonal workers, the self-employed and those who work on commission.

Under our reforms, all people who fall into these categories would be able to purchase health insurance either individually or as part of a family plan with other relatives who may have other employment. Furthermore, these individuals and families could either purchase coverage on their own or as part of a larger group. But in all cases, the tax relief would go directly to individuals and families and would be based on need, not employment status.

In addition to purchasing coverage on their own as individuals or families, there are a number of other likely purchasing arrangements which I can envision the people you asked about participating in. For example:

1) Some college students would likely retain coverage under a family policy purchased by a parent, until they were ready to buy coverage on their own. Other college students might buy their own coverage while still in school. In exchange for the opportunity to market their products directly to a large number of students, insurers could be expected to offer discounts for policies purchased by students through their university or a student group. Of course, since these would be individual policies, the students could chose to retain them once they left school.

Given that students are young, generally quite healthy, and could become long-term customers if they keep their policies after leaving school, I believe insurers would be eager to market to them. Indeed, based on the belief that they can develop long-term customer relationships and brand or product loyalty, businesses such as banks and computer companies already offer special discounts on their products or services when purchased by students through their college or university.

2) Seasonal workers, such as farm workers or construction workers, might find it particularly advantageous to purchase coverage through an appropriate union. For these workers, the advantage of such an arrangement would not only be the possibility of discounts on their coverage but also the union's assistance in handling premium payments, and the tax relief they are eligible for, to ensure that they retain coverage year round despite seasonal fluctuations in income.

In other words, the union would make sure that a worker was not faced with a unaffordable premium payment when he or she was not working. Similarly, the union would make sure that the appropriate tax relief accrued to the worker during the course of the year, instead of the worker having to wait until he or she filed a tax return. Of course, if these workers obtained other, more regular employment, or even left the union, they could still retain their policies and make other payment arrangements through their new employers.

Such union sponsored coverage would have advantages not only for the workers but also for the unions and the insurers involved. The unions would be offering a very attractive service which they could use to recruit and retain members. The insurers would get much greater certainty that premiums would be paid, providing them with considerable savings on the costs they would otherwise expect to encounter with selling policies directly to seasonal workers.

For example, without the union assistance, insurers marketing to seasonal workers could expect much higher than average costs associated with marketing policies, collecting premiums, tracking address changes, and lapses in coverage and bad debt losses due to policyholders' fluctuating incomes. For the insurers, union involvement would make seasonal workers a more stable, financially less risky, and thus much more attractive, market to sell to. To get the business, the insurers would pass their resulting savings on to the union, which would in turn pass the savings on to the workers.

3) Many small businesses, self-employed individuals or those who work on commission would likely buy coverage through either a national or local professional society, trade association or business group. Indeed, the list of groups which could potentially create such arrangements -- as some have already done -- would fill dozens of pages. For example: Chambers of Commerce, Rotary clubs, Farm Bureaus, Boards of Realty, Bar Associations, the National Federation of Independent

Business, the American Institute of Architects, the National Restaurant Association, Associated Landscape Contractors, -- even Medical Societies, the Independent Medical Distributors Association and the Association of Health Insurance Agents!

The advantages of such arrangements to the individuals, groups and insurers participating would be similar, or even identical, to the advantages discussed above for union arrangements for seasonal workers.

Q: In your proposal there are several health insurance regulation reforms to control rapid increases in the cost of premiums. How do you plan to prevent insurance companies from shifting more of the cost of health care to the consumer by limiting the scope and extent of what they will pay?

A: As noted, beyond a basic required level of catastrophic coverage, individuals and families would choose the package of coverage that best suited their needs and preferences. Health insurers would likely offer a number of options on deductibles, coinsurance and covered services, as do insurers in other areas. Also, as in other types of insurance, policyholders could later choose to change the terms of their coverage, say, by trading a higher deductible for a lower premium or vice versa. But insurers would not be able to unilaterally change the coverage terms.

While insurers could be prevented by law from unilaterally changing coverage terms, this would not really be necessary. No one would want to buy any kind of insurance that did not contain an enforceable contractual agreement by the insurer not to unilaterally change the coverage terms. In other words, just as no one would buy a home, auto or life insurance policy under which the insurer could unilaterally change the coverage by, say, raising deductibles or reducing benefits at any time, so too, no one would want to buy that kind of health insurance.

Whether individuals and families chose to buy comprehensive coverage with high premiums and low out-of-pocket costs, or no-frills coverage with low premiums and higher out-of-pocket costs would be a matter of personal preference, with little financial impact. This is because the tax relief would be based on total health expenses (both out-of-pocket payments and insurance premiums), relative to income. Regardless of their specific purchasing decisions, all Americans would have an incentive to get the best deal on health insurance and medical care because they would pocket the savings.

Q: How would your proposal help the families who testified at the hearing?

A: Because, under our proposal insurers would be prevented from dropping coverage on sick individuals or families, or charging them experience rated premiums, the sort of problems encountered by these families would not be faced by similar families in the future. In addition, under our proposal, during the transition to the new system, insurers would be required to accept those individuals and families who are currently both uninsured and uninsurable and would not be allowed to charge them premiums more than 25 percent greater than the premiums for comparable coverage for similar individuals in good health. This would guarantee that such individuals would have affordable coverage under the new system.

Once covered under the new system, like everyone else, they would no longer need to worry about their insurer dropping their coverage or charging them high renewal premiums based on their own particular medical condition. Similar, additional regulations could also be included limiting the extent to which insurers could adjust premiums for health status when a child reaches majority and wants to convert from coverage under a parent's policy to individual coverage.

Furthermore, under our proposal, individuals and families with higher out-of-pocket medical expenses would receive greater tax relief. Currently, families such as the Weaver's and Renshaw's can incur substantial out-of-pocket expenses yet receive little or no tax relief on them. Finally, because health insurance under our proposal would be individual and family based, and thus portable, individuals would be free to pursue their desired careers and job opportunities without fear that their employment status might adversely effect their access to health insurance and medical care. Parents would no longer be forced, like Mr. Weaver or Mrs. Renshaw, to change jobs or careers just to get insurance coverage for a high risk child.

Q: How does your proposal meet the goals and criteria outlined by Ms. Brown and Dr. Nelson to meet the special needs of women, children and teens in gaining access to the health care system?

A: In her testimony, Ms. Brown listed six goals for health care reform. My reading of the criteria which Dr. Nelson provided in his testimony are that they are essentially the same as Ms. Brown's. The one significant difference is that Dr. Nelson gave as an additional criteria, "that plans incorporate consumer-oriented administrative policies and procedures that assure appropriate quality, utilization, efficacy and cost efficiency." Obviously, the whole purpose of our consumer choice health care reform proposal is to create a health system that provides powerful incentives for the maximum responsiveness to consumer needs and preferences.

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Because Dr. Nelson's other criteria are very similar to Ms. Brown's goals, in the interest of clarity and brevity I will simply restate each of Ms. Brown's goals, followed by statements as to how I believe our proposal relates to each goal.

Goal #1: All children and pregnant women have continuous access to health insurance.

Response: Our proposal is designed to provided universal, continuous coverage through the private purchase of health insurance and medical care with the support of targeted tax relief, combined with the continuation, in existing or modified form, of publicly financed health care programs for the most disadvantaged members of society.

Goal #2: Coverage is provided for a continuum of services that emphasize primary and preventive care and includes the diagnosis and management of a variety of diseases and conditions, as well as specialized care to handle complex health problems.

Response: Unlike other proposals, ours does not specify in great detail the coverage health insurance policies must contain. This is because we believe that the real goal of health care financing policy should be to ensure affordable access to needed medical care -- not just health insurance. Health insurance is simply one means of paying for medical care. In some circumstances, it is the preferable means. But in other circumstances, buying medical care directly is the preferable means.

Therefore, our proposals seeks through tax relief to encourage the purchase of both medical care and health insurance. Furthermore, by targeting more generous tax relief to those with lower incomes and/or higher health expenses, our proposal seeks to ensure that the disadvantaged will be able to afford the same access to medical care and health insurance as the rest of society.

Beyond a basic requirement to obtain catastrophic coverage, our proposal leaves decisions about how, from whom, and in what combination, people purchase health insurance and medical services up to individuals and families to decide for themselves. We believe that it is impossible for anyone, ourselves included, to design an ideal, detailed, one-size-fits-all package, that effectively meets all the varying needs and desires of millions of individuals and families.

Individuals and families are the ones best able to make these decisions for themselves and have the greatest, natural interest in obtaining the package of care and insurance which best suits their own circumstances. A proposal such as ours will allow many different people to obtain many different "best" solutions, while ensuring that they are encouraged to purchase medical care and health insurance and have the means to buy what they need or prefer.

Furthermore, as I noted in my written testimony, there are several reasons why I believe our proposal offers the strongest incentives of any for individuals and families to obtain, and insurers and medical providers to offer, preventive and primary care health services.

Goal #3: Health services are provided by qualified providers in a wide variety of settings that are effective in caring for children and pregnant women, especially the medically underserved. Similarly, the number and diversity of qualified providers offering services to this population are increased, particularly for those who are poor, high risk, or living in inner-city or isolated rural areas.

Response: One of the principle effects of our proposal would be to increase the health care purchasing power of the disadvantaged. Such policies, I believe, will serve to substantially reverse the trend of providers avoiding low-income individuals or areas because they cannot obtain adequate reimbursement for their services.

However, there will likely continue to be a need for government programs to target even more assistance to underserved areas. There is also a need for reforming major programs like Medicaid, which currently has, simultaneously, some of the highest per-capita costs and the worst service delivery record and provider reimbursements.

I believe the reforms we have proposed for the basic health system would, over time, serve to substantially reduce the costs of medical care and health insurance while simultaneously improving quality and benefit. This is because under our proposed reforms consumers would be rewarded with more money in their pockets for seeking better quality and benefits at lower cost, while those providers and insurers who offer better quality and benefit at lower cost would be rewarded with more business. The resulting system-wide improvements would make it much easier, both fiscally and administratively, for governments to improve publicly financed health programs for the most disadvantaged members of society.

Specific reforms of public health care programs could easily be included as part of a legislative package centered on our proposed reforms, or could be undertaken at a later date, or more likely, both. I am currently working on developing some Medicaid reform proposals, and we would be willing to add to our package specific reform proposals suggested by others. We are simply looking for what is likely to be most effective.

Furthermore, it may prove desirable to increase government funding for one or more targeted health programs. If that is the case, there are three options. First, reduce funding for some non-essential, non-health programs. Second, increase funding of certain health care programs at the expense of others. Third, increase taxes. I would find the first option the most desirable and the third option the least desirable. If it is a question of finding budget savings to offset expanded funding of health programs, I would be glad to provide the Committee with the numerous and detailed budget savings identified by my colleagues at The Heritage Foundation and described in the Foundation's publications on federal budget policy.

Goal #4: The future role of existing government grant programs in maternal and child health is explicitly considered in reforming the health care system, with regard to both the personal health services supported by these grant programs and to their planning, evaluation, and training functions.

Response: My response to this goal is essentially the same as my response to goal three above.

Goal #5: Cost management measures accommodate the special needs of children and pregnant women.

Response: As noted in my written testimony, I believe our proposal offers powerful incentives for primary and preventive health care. Furthermore, once consumers are able to pocket any savings on their medical care and health insurance, they will quickly find sound managed care programs and cost management measures which help them stay healthy or increase quality and benefit, to be good value -- and will choose to purchase them. However, consumers will have a natural incentive to shun policies whose cost management measures simply consist of placing obstacles in the path of policyholders seeking treatment or benefits.

As I noted in my oral testimony, one of the effects of a consumer-driven system will be to, "turn manage care into a system for helping people stay healthy, as opposed to what it has now become, as Ms. Brown pointed out, a demand control tool." As evidence in support of this contention, I would point to the fact that federal workers, who under FEHBP can pocket the savings from choosing a less expensive plan, voluntarily enroll in managed care plans at twice the rate that private sector workers are forced into managed care plans by their employers.

Goal #6: The administrative complexity of the health care system is substantially reduced from the perspective of both providers and consumers.

Response: Consumers and providers have a natural aversion to administrative complexity. Therefore, in a consumer-driven market, consumers would exert powerful pressure on insurers to reduce such complexity. At the same time, to attract individual policyholders, insurers would want to be able to offer policyholders automatic acceptance of their insurance by the best providers. But those providers will likely demand administrative simplicity as a condition of establishing closer relationships with insurers.

As I mentioned in my oral testimony, I conducted extensive interviews last year with executives of British private health insurance companies, who sell almost exclusively individual policies. One thing that made a significant impression on me in those interviews when we discussed the terms of their coverage, was their clearly expressed aversion to having, "to much fine print" in their policies. They were afraid that if they made their policies too complex they would induce their policyholders to switch coverage to insurers offering simpler policies. I think we all want to see the day when American health insurers exhibit the same attitude.

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May 21, 1992

Sarah S. Brown, Senior Study Director
National Forum on the Future of
Children and Families
Institute of Medicine
2101 Constitution Avenue, N.W.
Washington, DC 20418

Dear Ms. Brown:

I want to express my personal appreciation to you for appearing before the Select Committee on Children, Youth, and Families at our hearing, "Health Care Reform: How Do Women, Children, and Teens Fare?," on May 2, 1992. Your testimony was important to the work of the Committee.

The Committee is now in the process of preparing the transcript for printing. It would be helpful if you would go over the enclosed copy of your remarks to assure that they are accurate, and return the transcript by Monday, June 1, with any necessary corrections.

In addition, I would appreciate a response in writing to the following questions for inclusion in the record:

1. Which of the seven proposals that you analyzed comes closest to meeting the most important goals as you defined them? Which of the proposals would most reduce the legal and access barriers to care faced by teens, as identified by Dr. Johnson? Do any of the proposals confront the parental consent or confidentiality issues that affect teens?
2. Which of the seven proposals you analyzed would benefit or ameliorate the problems experienced by each of our families who testified at the hearing?

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3. In general, which approach -- a multi-payer or single-payer system -- benefits children and teens the most? What are the advantages or disadvantages to insuring the best possible care for children with an employer-based system?

4. Does a tax-based or free market-based approach to health care reform meet any of your goals? Why or why not?

5. In terms of reducing administrative complexity, do any of the proposals require the development of a single insurance claim form? Would mandating the development and use of such a form be useful?

6. Could you provide an up-date on the status and funding of the National Health Service Corps?

Sincerely,

Pat Schroeder

PATRICIA SCHROEDER
Chairwoman
Select Committee on Children,
Youth and Families

Enclosure

PREPARED STATEMENT OF MARGARET FELDMAN, WASHINGTON REPRESENTATIVE, NATIONAL CONFERENCE ON FAMILY RELATIONS, 1992 COORDINATOR, CONSORTIUM OF FAMILY ORGANIZATIONS, WASHINGTON, DC

All those listening to the testimony of the families at the Committee's May 5th hearing on "Health Care Reform: How Do Women, Children, and Teens Fare" must have been impressed with the terrible impact of illness on those families. The National Council on Family Relations and the Consortium of Family Organizations, are pleased to be able to add our ideas for the record to bring to the attention of the Committee the need for a special focus on the needs of families. It is easy to consider the needs of the individuals in the family and still overlook and not make explicit the importance of families in health care. Our belief is that there are important family needs that need to be addressed above and beyond those of individuals.

In addition to all other criteria for health care reform, we need criteria for FAMILY FRIENDLY HEALTH CARE.

The Consortium of Family Organizations (COFO), is composed of the American Association for Marriage and Family Therapy, the American Home Economics Association, Family Resource Coalition, Family Service America, and the National Council on Family Relations. As a group, our five organizations comprise nearly 50,000 family professionals working with families in every state of the Union and Canada, faculty members in every major university in the nation, nearly 300 family agencies and more than 2000 family resource programs providing services to millions of families annually, and more than 10,000 volunteer board members.

COFO is nonpartisan and nonsectarian and is involved with families of all ethnic groups. While agreeing that the child-rearing stage of family life is of critical importance, COFO's broad family focus includes relationships between members of different generations and relatives who do not live in the same household.

COFO has four main goals:

1. To raise policymakers awareness of the diversity and complexity of family life and of the myriad ways in which government and institutions positively and negatively impact upon families throughout the life cycle.
2. To promote the family unit as a central focus of data collection, research, policy analysis and program evaluation.
3. To monitor and assess the impact of proposed legislation and executive actions on families and family life.
4. To encourage informed debate about governmental and institutional reforms needed to ensure a family focus in policymaking.

It is in accord with these goals that we are presenting this document for the record in regard to the national health care reform debate. Just as it is important to hear from doctors and insurers, we feel it is important for policy makers to hear from consumers. However, most frequently consumers are defined as individuals. In this national debate on health care it is crucial that families should be given a central position because it is in families that people are shaped and supported in their health behaviors, cared for in their illnesses, and at times,

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subjected to aversive influences which require intervention by medical, mental health, and social services professionals.

PLACE OF FAMILIES IN A NATIONAL HEALTH CARE PROGRAM

The Department of Health and Human Services, after a three year period of conferences and preliminary work, set forth its goals for the nation in a 1991 publication, Healthy People 2000. The goals are: "to increase the span of healthy life for Americans, reduce health disparities among Americans, and achieve access to preventive services for all Americans". While not explicitly emphasizing the place of families, the book does cite the family as "the primary context in which health promoting activities occur and is therefore potentially the most immediate source of health-related support and education for the individual."

See our Rationale for FAMILY FRIENDLY HEALTH CARE

But prevention and healthy living cannot do it all. Disease and disability also occur and families have to turn to the medical establishment for treatment. At times this becomes an overwhelming task, recognized in Healthy People 2000. "As the burdens of a family increase, its very spirit is threatened and the need for community support becomes still more crucial, not only to the well-being of its members but also to its survival."

Healthy people are the result of a "shared responsibility". Families, communities, employers and the government itself must be part of that shared responsibility, as acknowledged by Healthy People 2000.

We have drawn up a set of Preliminary Principles for FAMILY FRIENDLY HEALTH CARE which includes community responsibility.

At a 1991 National Center for Health Statistics conference called to discuss the HHS goals, Thomas L. Campbell,M.D., an NCFR member from the University of Rochester School of Medicine delivered a paper entitled, "The Role of the Family in Meeting the Nation's Health Objectives". He points out that almost every area discussed in this report is either a family activity or strongly influenced by the family: heath promotion, including the negative behaviors of violence in the family; health protection, including injuries and oral health; and preventive services, which involve maternal and infant health, cancer, HIV and STD infections and immunizations.

Professor Campbell writes that families are important because of two "pathways" or "mechanisms" which effect health. The first is the behavioral, and the second is the psycho-social.

In the behavioral aspects of daily living, from family modeling and teaching the behaviors of nutrition, smoking, drinking and exercise are all learned and maintained. Very negative behaviors of violence and punitiveness are also learned. For healthy behavior, the best way to get change and compliance to a regimen is to have family participation and support.

The qualities of family relationships, the psycho-social aspects, can have a physiologic effect on the immune system, on depression, and self-reported poor health. Other effects may be shown by future research. A family centered physician and/or health care program may be especially valuable in forestalling the onset of diseases to which people have a predisposition, promoting compliance which will lead to optimum recovery and in identifying and getting help for family violence.

Health also affects the quality of relationships. When one child or adult needs excessive medical attention, tensions arise in families which may lead to jealousy among siblings, by children against the adult, or may actually lead to divorce as spousal tensions and disagreements become very severe.

Since the hearing was addressed to the needs of women, children and teens, each expert witness properly focused on their particular segment of health care need. Our concern is that focus only on the individual segments of women and children, adolescents, and, in another hearing, of older people, may cause us to lose sight of the fact that the family must also be addressed as a system. Our view is to consider "families" to be dynamic, interactive systems

Families are dynamic interactive systems consisting of all ages and compositions, not only mothers or parents and their children. Families are also composed of adults who support each other as spouses, committed partners, siblings and all those relatives and non-relatives who care for and support others of all generations. In a system, what effects one effects all; the infirmities of one has repercussions on all. An infectious disease suffered by one may spread to others and mental or emotional conflict and distress can seriously disorganize a family.

Services need to be addressed to the system needs of the family. Mental health services and counseling are an integral part of any comprehensive program. These services must be financially available as needed.

FAMILY FRIENDLY HEALTH CARE must include mental health services and explicit inclusion of families in the treatment plan and financial arrangements.

DEFINITION OF FAMILIES.

Given the complexities of families today, consisting of many contractions and expansions of the traditional family through single parent families to blended families, multigenerational and intentional families, it becomes necessary to develop new definitions.

Today's families are pluralistic, consisting of a wide variety of forms. Professor William Dougherty in a recent Psychology Today article on the new Pluralistic Family, describes what he calls the new family ethic which should emerge. This ethic includes commitment, caring,and community from the old ethic, but adds equality, and diversity.

Commitment and care are still considered by many to be the essential characteristics of family life, but Professor Dougherty thinks that our society has moved away from a national consensus on the importance of community. Families have to be part of the community and the community has to take some responsibility for the families. FAMILY FRIENDLY HEALTH CARE is part of this community support.

Many citizens and policy makers cannot accept the diversity of new family forms. These new forms will be evaluated by whether they provide commitment and care, and community support will be given to encourage and support these values.

The factor of equality within families is a modern goal--full personhood for men and women. This is perhaps the most difficult part of the transition from the traditional family to the new ethic and is causing the most resistance. To implement this value may take many years but should be included in our criteria.

Traditionally, and still today, in most families women are primarily responsible for health care. This ascription of caregiving to women alone may have negative consequences for women and for men. Although many women enjoy being the caregiver, being looked upon as the only caregiver has served to keep women in lower paying jobs, given them the reputation of being unreliable employees since they are the ones called upon for family care, and given them lower pensions in retirement because of their lower attachment to the work force.

For men, being discouraged from the caregiver role has denied them the opportunity to experience a major part of life. Fathers who take time to be caregivers to their children find it very satisfying and those who missed caregiving of children often regret it in later life. Today, we find many men who find deep satisfaction in being able to care for their children, wives, and partners. Men now have joined the caregiving community and their role in caregiving should be recognized and encouraged in FAMILY FRIENDLY HEALTH CARE.

Women, in their reproductive role are crucial to the health of society and their care is, and should be, a major focus of FAMILY FRIENDLY HEALTH CARE. We support all the goals presented by Dr. Brown and Dr. Nelson. We feel, however, that attention to male partners needs to be expanded in the care given in pregnancy and child birth.

The health of women as persons has received much less attention than that of men, even though women are major users of health care services. Recent development of a women's Health Care Initiative at NIH and the recently organized Campaign for Women's Health are calling to attention the special needs of women. We have made use of and adapted the Principles of the Campaign for Women's Health in our criteria for FAMILY FRIENDLY HEALTH CARE.

The Women's Campaign calls for actions to address family violence. In 1980, the National Crime Survey based on telephone interviews estimated 192,000 family assaults resulting in 39,900 visits to a physician and total health care costs of approximately $44,393,700. FAMILY FRIENDLY HEALTH CARE should bring attention to the increasing costs to society and community of the escalating violence in our homes and streets. This is a part of health care.

The special needs of adolescents were well described at the hearing. The special interactional problems of adolescents and their parents were clear, showing the need to help adolescents and their families negotiate the transition to adulthood and self-responsibility as an integral part of in FAMILY FRIENDLY HEALTH CARE.

A FAMILY FOCUS FOR HEALTH CARE: A SET OF PRINCIPLES TO USE IN ASSESSMENT OF HEALTH CARE REFORM PLANS

RATIONALE for the need for FAMILY FRIENDLY HEALTH CARE.

Families are partners in all forms of health care:

Families, ideally, provide the health care needed for all members
Families make arrangements for the professional care needed.
Families carry out the home proceedures recommended by professionals.

Children do not go to get medical care on their own:
Families are necessary to make arrangements and take them.

Children do not get immunizations by themselves:
Families are needed to get children to the doctor.

Children do not follow the doctor's prescription:
Families care for children by following the doctor's prescription.

Children do not arrive at school without habits of eating and caring:
Families have taught them, by modeling or instructing them.

Adolescents' use of medical care is strongly influenced by their family relationships.

Spouses who become infirm or sick who cannot care for themselves usually turn to:
Their families: Wives and husbands, spouses, and other relatives care for each other.

Older parents who need support and ultimately long term care are often cared for by:
Families of all generations.

Any NATIONAL HEALTH PLAN must be evaluated, in addition to all other criteria, by the degree to which it is FAMILY FRIENDLY.

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PRINCIPLES OF FAMILY FRIENDLY HEALTH CARE:

These principles were designed to supplement, not replicate or repeat other health care reform principles developed by other groups which define the need for universal, accessible, comprehensive and affordable care for all. We offer these criteria as some additional ways health care proposals should take the special needs of families into account.

1. Family Friendly Care is FINANCIALLY ACCESSIBLE:
   - -to all families without worry about family finances.
   - -with no linkage to employment status and no job-lock. No breadwinner should have to select a job or give up training in order to get family health care.
   - -without concern for pre-existing conditions. No parents should have to worry that a child with serious health problems during childhood will be excluded from employment in adulthood because of pre-existing condition.
2. Family Friendly Care is AVAILABLE:
   - -preferably in the community, for primary care.
   - -in one central place for treatment of all family members so that what is "going around" is not treated by one doctor for a child and another for the adult.
   - -by public transportation for those without cars, and within reasonable distance.
   - -at night and weekends when employed family members do not have to lose work time except for emergencies.
   - -with some provision for care for a second child when the family is occupied with care for the first.
3. Family Friendly Care INCLUDES:
   - -primary care
   - -specialist care
   - -prevention services including immunizations.
   - -screening for abnormalities
   - -glasses and hearing aids and prescription drugs as needed.
   - -family centered mental health care
4. Family Friendly Care CONSIDERS FAMILIES AS PARTNERS:
   - -Families are treated with dignity and their opinions and needs taken into account.
   - -The special circumstances of rural and farm families, as well as urban families are considered.
   - -Services take into account the culture and language of the family.
   - -Families are given needed information, training , and mental health support in times of serious illness, and the respite necessary during long term care.
5. Family Friendly Care is DEVELOPMENTAL.
   - -Includes prenatal care, birth in a supportive environment, and post-natal care.
   - -includes outreach.
   - -Provides age-appropriate care.
   - -Helps adolescents move to adulthood and take responsibility for their care.
6. Family Friendly Care is EDUCATIONAL. Families are offered opportunities to learn:
   - -How to foster normal development; physical, intellectual and emotional.
   - -What is normal and what is deviant enough to worry about.
   - -What to look for to provide correct information for the specialist.

-What to do to get children ready for school.
-How to make sure their adolescent children, both boys and girls, get the information they need to successfully negotiate the transition to adulthood.
-How to understand the needs and feelings of older members and the family members who care for them.

-Strategies to cope with the stresses of family living due to unemployment, financial strain and family loss.

7. Family Friendly Care provides for a reasonable ratio of PRIMARY CARE PROVIDERS AND SUBSPECIALIATION PROVIDERS.
8. Family Friendly Care is FOSTERED BY COMMUNITIES AND EMPLOYERS.
   -Family and medical leave is essential.
   -Employers, public and private, should implement family friendly policies to allow families to provide for the health needs of children and the elderly.
   -Communities should take families into account as they locate and support health care facilities.
   -Services may need to be taken to families.
   -Communities take responsibility to find and remedy health hazzards in their area which make it more difficult for families, especially those who live in blighted urban areas.
   -Rural areas need health practitioners sympathetic to the stresses of rural living.
9. Family Health Care is often provided by women but all CAREGIVERS NEED CARE.
   -The health of caregivers, both women and men, is necessary to keep the rest of the family well.
   -All health services provided by caregivers in the home should be considered part of society's work and caregivers should not be penalized in wages or benefits for family work.
   -The special needs of single parent households should be considered.
10. RESEARCH NEEDS INCLUDE:
   -document and analyze the effect of families on the health outcome of proceedures.
   -develop and evaluate methods for maximizing family support in times of illness.
   -further document the impact of family violence on the health care system.
   -develop and evaluate means of preventing and reducing violence in families.
   -assess the value of using practitioners of various levels as promoting family health.
11. TRAINING
   -Health care practitioner training should include understanding of families as partners in health delivery and the operations of family systems.
   -Women practitioners at all levels need to be trained and valued in order to promote equity.
12. ADVOCACY
   -Families and their advocates should make the needs of families visable and necessary for health planning and should lobby as strongly for their needs as other interest groups.

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